

**South Asian parents' experiences of adjustment following a  
diagnosis of learning disability and/or an autism spectrum disorder  
for their child: a grounded theory approach**

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## **Declaration**

I, Alia Ul-Hassan, declare that this thesis was written by me and that I conducted the work detailed herein. This work has not been submitted for, or accepted in, any previous degree.

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## ABSTRACT

**Background:** There is a great deal of literature pertaining to White parents' experiences of having a child with a learning disability. Some of this literature focuses on parents' experiences of the disclosure of diagnosis of learning disability and/or an autism spectrum disorder, as well as how they come to accept and adjust to a diagnosis. However, very little research has investigated the experiences of South Asian families.

**Materials and methods:** This qualitative study used a grounded theory methodology to explore the experiences of seven South Asian parents in relation to the disclosure of diagnoses as well as issues relating to adjustment post-diagnosis. Semi-structured interviews were used to gather data.

**Results:** The results outline variable experiences in relation to the process of adjustment following a diagnosis. Four core categories were derived from the data to represent stages in a hypothesised model of adjustment. These were: 'obtaining a diagnosis'; 'constructing meanings'; 'finding possibilities for action'; and 'reconstructing roles and identities'. These core categories were embedded within a number of important contextual influences.

**Conclusions:** The theoretical and clinical implications of the hypothesised model of adjustment are discussed. A methodological critique is provided before outlining reflections on the findings generated.

# CHAPTER 1      INTRODUCTION

## 1.1      Background to chapter

The introduction will begin by giving an overview of the ethnic profile of the UK and will discuss the prevalence, definition and social construction of learning disabilities/ASDs. The literature in relation to the impact on parents of having a child with a learning disability and/or an ASD will be explored as well as considering pre-diagnosis, diagnosis and post-diagnosis issues. Relevant cultural issues in relation to these areas will also be discussed before concluding with the aims of the current study.

## 1.2      Ethnic composition of the UK

One of the most significant social shifts that is occurring on a world-wide scale is the increasing heterogeneity of society (Friedman, 2006). The ever-changing UK demography mirrors this worldwide shift as it becomes increasingly diverse and complex in terms of ethnicity, culture, language and religion. The UK census revealed that the non-White population of England was 9% in 2001, a rise of 3% from the last census in 1991 (Emerson & Hatton, 1999). In Scotland, the non-White population at the last census count (2001) was 2% or just over 100,000 of the total population (Scottish Executive, 2004). The majority of the total ethnic population in Scotland (over 70%) was found to be of a South Asian origin <sup>1</sup>i.e. Pakistani, Indian or Bangladeshi (Modood *et al.*, 1997). The 2001 Scottish census also revealed that ethnic minority groups have a higher proportion of younger people than the UK population as a whole. Hatton (2002) reviewed UK population trends in terms of the learning disability <sup>2</sup> population and

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<sup>1</sup> In line with Modood *et al.*'s (1997) definition of 'South Asian', the current study uses the term "South Asian" to describe individuals who are from Pakistani, Indian or Bangladeshi backgrounds. The researcher, however, is aware that South Asians are not a homogenous group.

<sup>2</sup> It is important to acknowledge at the outset that there are international variations in the terminology used to describe learning disability. For example, in the USA the terms "intellectual disability" and "mental retardation" are commonly used. However, the term "learning disability" is the preferred option in the UK (British Psychological Society, 2000a), and will therefore be used throughout this study.

concluded that the increase in ethnic diversity as described above is also apparent in the population of people with severe learning disability.

### **1.3 Prevalence of learning disability and ASDs in children and young people**

According to UK prevalence studies based on total population estimates, 2%-3% of children have a learning disability (Scott, 1994). Epidemiological data also suggests that ASDs affect around 115,000 families in the UK (Midence & O'Neill, 1999). The majority of epidemiological research does not include data relating to the ethnic profile of people with learning disabilities. However, Emerson and Hatton (1999) have suggested a projected 70% increase in the number of non-White people with learning disabilities in the UK from 1999 to 2021, compared to an increase of 3% in the White population. By 2021, it is estimated that 7% of all British people with learning disabilities will be of South Asian origin (Emerson & Hatton, 1999).

The prevalence of learning disabilities in South Asian communities has been a source of contention over the years, with several authors suggesting that there is a higher prevalence in South Asian communities compared to White communities (e.g. Azmi *et al.*, 1996; Emerson *et al.*, 1997) and others suggesting that there is no difference (e.g. McGrother *et al.*, 2002). However, it is acknowledged that accurately estimating the prevalence of learning disability across ethnic groups is problematic in the absence of rigorous epistemological research. Nevertheless, it remains the case that there is a significant over-representation of South Asian children in UK schools for children with severe learning disabilities (Di Terlizzi *et al.*, 1999; Emerson & Robertson, 2002).

Several reasons have been postulated for this higher prevalence in ethnic minority communities. Klingner *et al.* (2007) state that being a person from an ethnic minority does not cause learning disabilities in and of itself, but that they are more likely than people from White communities to have lower socio-economic status, thus increasing their risk for acquiring a learning disability. Indeed, many authors have discussed the

well-established link between socio-economic position and the prevalence of learning disabilities (e.g. Emerson, 2004; Fujiura, 1998; Fujiura & Yamaki, 2000). Furthermore, Emerson *et al.* (2006) state that in Britain, children in the 20% of most socio-economically disadvantaged families had more than four times the risk of learning disability when compared with those in the least disadvantaged 20%.

Other social and economic factors commonly cited as contributing to a greater risk of learning disability in South Asian communities include: a high incidence of low birth-weight; limited access to prenatal care; greater risk of exposure to trauma due to illness or injury; greater exposure to environmental toxins; and higher instances of infectious diseases (Fujiura & Yamaki, 1997). There has also been speculation that high rates of consanguineous (first-cousin) marriages in South Asian communities is associated with later learning disabilities in offspring (e.g. Teebi & El-Shanti, 2006; Yaqoob *et al.*, 1995). However, Ahmad (1996) states that while the “consanguinity theory” is widely ascribed to by health professionals, there is little robust research to back up this speculation.

## **1.4 Definitions**

### **1.4.1 Definition of learning disability**

Internationally, various classification systems are used to define and diagnose the presence of a learning disability e.g. the DSM-IV (American Psychiatric Association, 1994) and the ICD-10 (World Health Organisation, 1992). Despite minor variations in wording and emphasis, both agree that three criteria must be met before a child or adult can be classified as having a learning disability i.e. a significant impairment of intellectual functioning (i.e. IQ <70); a significant impairment of adaptive/social functioning; and onset before the age of 18 years. The British Psychological Society (2000a) also provides guidelines for classifying the severity of a learning disability based on standardised IQ scores where “significant” impairment is classified by an IQ of between 55 and 69 and a “severe” impairment by an IQ of 55 or less.

Various controversies surrounding the term “learning disability” and its measurement have been discussed over the years. For example, Whitaker (2003) notes that the cut-off points to classify someone as having a learning disability are arbitrary and tell us little about an individual’s ability to cope. Concerns relating to IQ drift and discrepancies between tests are also noted (Leyin, 2004). Others have raised concerns that the scales used to measure IQ (typically the Wechsler scales) may not be applicable to certain groups e.g. those who have significant cognitive or sensory impairments (Banis & Jones, 2003), those who are disadvantaged socio-economically and those of different cultural/linguistic and minority backgrounds (Murray *et al.* 2003). Indeed, the cultural bias of IQ testing is well recognised but it is still often administered in a ‘culture-blind’ fashion (O’Hara, 2003). Additional concerns relate to the negative impact that IQ assessment can have on an individual’s self-concept (e.g. Hastings *et al.*, 1993).

The recognition that learning disabilities are socially constructed has led to an awareness of the limitations of traditional ways of identifying and labelling someone as having a learning disability. This will be further explored in this chapter.

#### **1.4.2 Definition of Autism Spectrum Disorders**

The term ‘autism spectrum disorders’ covers pervasive developmental disorders that share common symptoms, including autism and Asperger syndrome. Both the DSM-IV and ICD-10 present features by which both may be recognised, referring to areas of development rather than specific behaviours. The bases of both diagnostic systems relate to differences in three areas of development: difficulties in emotional and social understanding; verbal and non-verbal communication; and flexibility in thinking and behaviour.

Although autism and Asperger syndrome share similar characteristics and are viewed by many as lying on a continuum, they are nonetheless quantitatively and qualitatively different (Howlin, 1998; Wing, 1998). Autism is often considered to be a severe disability

because of the intense lifelong effects it has on the individual and his or her family (Dyches *et al.*, 2004). It is usually present from birth or very early in development, and frequently co-exists with learning disability. In individuals with Asperger syndrome, there are usually no clinically significant delays in cognitive development or adaptive behaviour (American Psychiatric Society, 1994). These children's differences manifest as impaired social interaction and the development of restrictive, repetitive patterns of behaviour and interests that commonly do not create obvious problems until school age (Hyman *et al.*, 2001). For this reason, Asperger syndrome is generally diagnosed at a later age, whilst autism can be diagnosed reliably around two years of age by experienced clinicians (Lord & Spence, 2006). It is important to note that an individual may have an ASD without a co-existing learning disability. In addition, a high number of autistic traits are likely to be found in people with learning disabilities even if the criteria for a formal diagnosis of an ASD are not met (Bhaumik *et al.*, 1997).

As with the diagnosis of learning disabilities, concerns relating to the diagnosis of ASDs have been raised. These typically relate to the often ambiguous and contingent quality of diagnoses since they are behaviourally-based and made against developmental markers, and therefore, are open to change as a child develops (McLaughlin, 2005).

#### **1.4.3 Disability as a social construct**

It is now commonplace to accept that learning disabilities are socially constructed. Anthropological work suggests that all societies may make distinctions between 'competent' and 'incompetent' people (Jenkins, 1998). As a result, definitions, measurement and prevalence of learning disabilities has varied enormously within both high and low-income societies over time and internationally (Trent, 1994; Wright & Digby, 1996). Fryers (1993) notes that this variance can be accounted for by social, political, economic and cultural changes within society throughout history.



It is clear that the definitions of learning disability and ASDs are based on a medical model of disability. Indeed, Emerson *et al.* (2007) note that westernised countries have developed highly systematised methods for identifying learning disability, partly through shaping the construct of learning disabilities itself and partly through the development of standardised measurement tools. However, critics of the medical model note the controversy in relation to defining disability in this way and the values that become attached to it (e.g. Morris, 1993). They further question the fact that its narrow focus on the 'medical condition' or 'impairment' often reduces disability to a form of 'personal tragedy'. Furthermore, Klotz (2004) says that given the dominance of the medical model, people with learning disabilities are only ever professionally 'known' in terms of their 'disabilities' or 'abnormalities'. She argues that this then informs the way that such people are perceived and treated in ways that pathologise and objectify them.

Bogdan and Taylor (1976) are widely cited in literature discussing the social construction of learning disability. They have stated that the 'scientific aura' which surrounds learning disability masks the subjective moral and cultural values and judgements associated with it. They note that terms such as 'learning disability' tell us little about the individual given such a label, but more about society and the methods by which those in power perceive and categorise people who fail to fit the increasingly complex demands of modern society (Bogdan & Taylor, 1976). Indeed, Emerson *et al.* (2007) explain that the construct of learning disability currently used in westernised societies has been developed to meet the needs of a specific group of largely urban and industrialised countries at a particular point in time e.g. the construct of intelligence places much emphasis on the abstract reasoning skills required for economic productivity within societies that value literacy and numeracy. Similarly, the construct of adaptive behaviour emphasises independent functioning within high income societies.

In addition to meeting particular societal needs, Emerson *et al.* (2007) go on to suggest that the construct of learning disability also reflects dominant values within high income societies. In cross-cultural terms, these societies have been characterised as highly individualist (as opposed to collectivist), defined in terms of: the definition of the self as personal or collective, independent or interdependent; personal goals having priority over group goals or vice versa; an emphasis on exchange rather than on communal relationships; and the relative importance of personal attitudes versus social norms in a person's behaviour (Triandis, 1995).

However, the construct of a learning disability based on notions of individualism has been shown to be less relevant for ethnic minority groups who are often thought to be more collectivist in nature (Emerson *et al.* 2007). This is reflected in their understandings of learning disability which relate to collectivist values. For example, some family members within some ethnic minority groups seem more likely to value and define their children's competence in terms of interdependence, appropriate social behaviour within the family context, and showing respect for family members and their cultural practices (Magana, 1999; Rao, 2006).

Emerson *et al.* (2007) note the tension that can arise when the dimensions of competence valued by some ethnic minority communities come into conflict with "Western" constructions of incompetence. They note that these tensions may be more likely to arise at particular times e.g. during the transition from child to adult services, particularly in terms of placement outside of the family home for the individual with learning disabilities (Blacher, 2001). Various researchers suggest that when Western constructions of incompetence are imposed on groups of individuals who do not necessarily share such constructions, and especially when they are allied to sufficient professional infrastructure and power, it can lead to families being perceived by professionals as obtrusive, over-protective and in denial about their child's learning disability (e.g. Mpfu, 2002). As well as a clash of values, Hatton (2002) notes that conflicts such as

these are also likely to be a function of the socio-economic position of families, language issues, and racism on the part of service systems.

## **1.5 Parents experiences of receiving diagnoses for their children**

### **1.5.1 Introduction**

Researchers have traditionally assumed a psychopathological stance in considering the experiences of families who have a child with a learning disability. For example, Solnit and Stark (1962) suggested that mothers of children with disabilities inevitably mourned the loss of their idealised child. This assumption resulted in stage theories which assumed that mothers went through stages involving shock, emotional disorganisation, and emotional reorganisation as they adjusted to the trauma of having a child with a learning disability. Others felt that mothers harboured 'chronic sorrow' that was exacerbated at key transition points in their child's development (Olshansky, 1962). However, Blacher (1984) notes that the empirical basis and usefulness of such stage models are questionable, due to the dangers of using them to stereotype families rather than help them.

More recently, research has moved to a position that families are stressed but coping as best they can. Even more recent research explores the idea that having a child with a learning disability and/or an ASD can have many positive effects on families. Despite a lack of conceptual clarity over what is meant by positive impact or related terms, Hastings and Taunt (2002) advocate a position where researchers set positive experiences against the better researched negative effects if a fuller understanding of parental acceptance, adjustment and coping post-disclosure of diagnosis is to be achieved.

There are now a significant number of studies which examine not only the role of parents in a child's development and the impact of a child with disabilities on the

family, but also the experiences of parents in obtaining a diagnosis and adjusting to its consequences. Green (2002) notes that the diagnosis of a learning disability and/or an ASD can be traumatic and bewildering for many parents. Indeed, it has been noted that 'disclosure' (the first communication of a diagnosis of a learning disability and/or an ASD in a child to the parents) is an experience which is often never forgotten (Sharp *et al.*, 1992).

Most of the research in this area discusses issues relating to the following stages: pre-diagnosis, diagnosis, post-diagnosis and adjustment.

### **1.5.2 Pre-diagnosis**

During the period prior to obtaining an adequate diagnosis for their child, parents often begin to notice difficulties with their child's development and will usually have made numerous visits to a GP or paediatrician to discuss their concerns (Quine & Rutter, 1994, Smith *et al.*, 1994). For example, in relation to ASDs it has been noted that parents often begin to notice behavioural and communication difficulties when their child is as young as 17 months (Coonrod & Stone, 2004). Using UK samples, Howlin and Moore (1997) and Howlin and Asgharian (1999) found autism diagnosed on average at 5.5 years and Asperger syndrome at 11 years. However, despite the decreasing average age at which ASDs have been diagnosed in recent years, parents are still often faced with a slow and frustrating period of uncertainty, confusion and worry that can be characterised by parental feelings of self-blame as well as severe stresses on family relationships (Midence & O'Neill, 1999). Furthermore, parents can often find themselves in the position of trying to convince clinicians that there is a need for specialist assessment (Goin-Kochel *et al.*, 2006). Qualitative studies carried out by Gray (1995) and Schall (2000) have found that parental dissatisfaction in relation to the diagnostic process can be partly attributed to clinicians' minimisation of parents' concerns about their child's development and subsequent diagnostic delays. During this time parents may be given

false assurances, or their child may even be given a diagnosis that is incorrect, misleading or vague (Mansell & Morris, 2004).

Various researchers have discussed the reasons why clinicians are in a difficult position when they first suspect a learning disability and/or an ASD. For example, Quine and Rutter (1994) note that clinicians do not want to destroy a parent's hope, nor to foster false optimism. In relation to ASDs, Goin-Kochel *et al.* (2006) argue that since behaviour difficulties and speech delays are not unique to children with ASDs, clinicians tend to be cautious about diagnosing incorrectly to prevent needless tension in families whose children are developing typically, albeit at a slower rate. It has also been shown that in 30%-50% of children with a learning disability, it is not always possible to state a certain diagnosis (Daily *et al.*, 2000). Delays in diagnosis are, therefore, often due to the need to observe the child, sometimes over long periods of time, before a full diagnosis can be made (where possible). However, the gap between a parents' first concerns and age of diagnosis can be problematic in light of evidence suggesting that early identification of learning disability and/or ASD can be beneficial in reducing the impact of early deficits on later functioning (Mundy & Crowson, 1997), by allowing access to appropriate interventions and educational programmes targeted at both the child and family (Shattuck & Grosse, 2007).

### **1.5.3 Diagnosis**

The process of finally receiving a diagnosis leads to mixed emotions in parents. Many experience relief that someone else has corroborated what they had initially suspected (Midence & O'Neill, 1999) and receiving a diagnosis often provides a way to explain their child's difficulties to themselves and to others. Other parents are described as experiencing shock, disbelief, anger, hopelessness, denial and confusion (Seigel, 1997). There are a number of studies which explore parents' experiences of and satisfaction with the diagnostic process. Most of this research has focused on retrospective parental reports of satisfaction and while there are concerns about potential biases in parental

recall, satisfaction is consistently shown to be low (Pearson *et al.*, 1999; Quine & Pahl, 1987; Sloper & Turner, 1993). In relation to ASD diagnoses, Goin-Kochel *et al.* (2006) carried out a web-based survey of 494 parents and found that about 40% were dissatisfied with the diagnostic process. Parents were more satisfied when they received diagnoses at earlier ages but more dissatisfied the more professionals they had to see before a diagnosis was given. Parent education and income were associated with earlier diagnoses and subsequent higher satisfaction. The authors note that this raises questions about equitable pathways to a diagnosis for families of low socio-economic status who, they argue, may have fewer resources from which to draw support and information and therefore may put forth less of a 'push' towards clarifying their children's issues and needs. Other qualitative studies suggest that parental satisfaction is related to the certainty of the stated diagnosis (e.g. Graungaard & Skov, 2006)

While many studies attest to parent dissatisfaction with the diagnostic process, Cottrell and Summers (1990) have shown that parents remain relatively satisfied so long as they are kept fully informed about the reasons when a firm diagnosis cannot be made. Further evidence exists in relation to ASD diagnoses showing that dissatisfaction with the disclosure of diagnosis is not inevitable. For example, Brogan and Knussen (2003) carried out a study using a self-report measure with a Scottish sample comprised of 92 mothers and 34 fathers. Whilst taking into account the difficulties inherent in using self-report measures and the low return rate obtained in this study, it revealed that more than half of the sample were satisfied or very satisfied with the disclosure. Furthermore, parents who were more satisfied felt that their opinions were taken seriously and were positive about the manner and communication skills of the professional handling the disclosure.

Indeed, various researchers have explored clinicians' practice in communicating a diagnosis to parents. In an early study, Cunningham *et al.* (1984) studied how Down's syndrome was reported to parents and found that they were presented with a picture of

struggle and grief, which impacted on their ability to cope and respond to their baby over the long-term. Cunningham (1994) has since discussed that the “grief” parents are said to experience when a diagnosis is given is not solely down to the news itself, but a product of the processes clinicians go through i.e. if the clinician assumes the news is “bad” and needs to be “broken”, it denotes a negative conception which is likely to be imparted on the parent. Indeed, McLaughlin (2005) has noted that medical approaches to diagnosis and disability generate an overly pathological approach to communication which can confirm for parents that this, indeed, is a dreadful thing that is happening to them and their child.

Hasnat and Graves (2000a) carried out interviews with 23 parents of children with developmental disabilities and showed that parents were more satisfied when the disclosing professional communicated well, had an understanding of parental concerns and was direct in manner. A number of other researchers have identified dissatisfaction among parents as being due to, in part, the way a professional communicates a diagnosis e.g. being unsympathetic, cold, insensitive and using language that is too difficult to understand (e.g. Cunningham, 1994; Graungaard & Skov, 1996).

As well as exploring parents’ experiences, various researchers have also explored clinicians’ practice in disclosure of diagnosis. For example, it has been found that their practice can be influenced by the perceived intellectual ability, educational and ethnic background of parents as well as their perceived emotional state (e.g. Hasnat & Graves, 2000b; Lipton & Svarstad, 1977).

Taanila *et al.* (2002) argue that while the communication skills of health professionals have improved over the last 20 years, it is important to keep in mind evidence suggesting that the initial experiences with clinicians can have a significant and lasting influence on parents’ ability to accept, adjust and cope with their child’s difficulties post-disclosure. In addition, Tate *et al.* (2002) note that poor communication between parents



and professionals during disclosure of diagnosis can result in mistrust and anger that influences future relationships between parents and professionals. However, it has been shown that when disclosures of diagnoses are handled skillfully, the communication of assessment findings can be a turning point for parents as they are helped to understand their child's needs and plan for their future treatment and well-being (Cottrell & Summers, 1990). In order to facilitate good practice in communication, various recommendations have been developed e.g. emphasising the need to undertake disclosures using everyday language which is free of medical jargon, allowing sufficient time to disclose a diagnosis and arranging follow-up support to discuss any issues relating to the diagnosis (e.g. Cunningham, 1994).

In addition to recommendations regarding communication of diagnoses, there has also been an emphasis on developing a collaborative relationship with parents and allowing them to play a key role in the diagnostic process. Researchers have showed that parents often expect to be cooperating partners with professionals and value being acknowledged as the experts on their own child (e.g. Graungaard & Skov, 2006). Indeed, a qualitative study carried out by Scorgie and Sobsey (2000) showed that when parents' knowledge is valued, a strengthened sense of purpose and self-affirmation in parents seems to follow.

Good *et al.* (1994) state that while drawing parents into the diagnostic process as active participants is essential, it is important to consider the references through which they draw meaning in the process. This is important in light of the fact that both professionals and parents bring with them existing discourses of disability that influence the way they discuss and frame a diagnosis. For example, Landsman (2003) argues that the medical model of disability maintains hierarchical models of medical practice which can often make it difficult for parents to speak for their children and challenge unnecessarily negative forecasts for what the future holds. Indeed, Graungaard and Skov (2006) found that parents expressed concern about the difference between themselves and clinicians'



perceptions of their child, whereby parents often focused on their child's possibilities while clinicians described their child in terms of disabilities and symptoms. However, other researchers have investigated the role that parents can also play in the medicalisation of difficulties by advocating for a medical explanation in hopes that it will open doors to supports as well as redefining their child with a legitimate condition (e.g. Conrad & Potter, 2000).

#### **1.5.4 Post-diagnosis**

Following the disclosure of a diagnosis, parents often face many difficult existential questions. Various models have been proposed to conceptualise the experiences of parents following diagnosis e.g. the "parent transformation process" model (Scorgie *et al.*, 2004). This model suggests that, following diagnosis, parents are confronted with a number of critical questions as they aim to cope with the diagnosis and move on. Such questions include: life trajectory identity-oriented questions (e.g. Who is my child? Who can they become? Who am I as a parent and who can I become? How will this diagnosis change life now and in the future?); existential meaning-oriented questions (e.g. Why did this happen? How can I make sense of it?); and personal and family choice-oriented questions (e.g. How are we going to react to and live with the diagnosis? What choices are available to us?).

In answering life trajectory identity-oriented questions, issues arise in relation to what Green (2002) calls a "double loss" – the loss of the child parents imaged, as well as a loss of their anticipated futures. Wilgosh and Scorgie (2006) found in their qualitative study that in the process of constructing new child images, parents spoke about the importance of focusing on the positive characteristics of their child. Wilgosh & Scorgie (2006) argue that professionals can help parents to answer these questions by supplying realistic but hopeful information about their child's diagnosis, and also by supporting the development of parental self-efficacy. In facilitating the process of image-making, the importance of adequate information is not under-estimated. Taanila *et al.* (1998) note

that information that parents are given upon diagnosis can profoundly shape the images they construct and subsequent feelings of confidence in managing their situation. Despite this, studies consistently report that clinicians underestimate parents' need for relevant, timely and accessible information at the time of disclosure of diagnosis (e.g. Hasnat & Graves, 2000a; Howie-Davies & McKenzie, 2007).

In relation to existential meaning-oriented questions, Meichenbaum and Fitzpatrick (1993, p. 711) assert that following a stressful event, people must "construct meaningful and acceptable interpretations that provide them with a source of predictability and control". Indeed, Wilgosh and Scorgie (2006) note that following a diagnosis for their child, a parent must make sense of the diagnosis and that religion and faith can provide a way of doing so for some parents. They further note that finding answers to "why" questions can be a long and difficult process for parents but that professionals can help by clearing up misconceptions that parents may have as well as gently and positively challenging unhelpful ruminations (Wilgosh & Scorgie, 2006). However, the importance of reflexive practice is not under-estimated by Wilgosh and Scorgie (2006), who note that clinicians should be aware of the extent to which they might shape the meaning-making process for parents by imposing their own constructions of disability (either consciously or unconsciously).

In answering personal and family choice-oriented questions, Nota *et al.* (2003) state that following a diagnosis, most parents actively engage in seeking strategies that will enable them to increase the management of their personal and family lives. Wilgosh and Scorgie (2006) found that rather than resigning themselves as victims of the diagnosis, their acceptance of it enabled them to seek solutions. This has been emphasised in other qualitative studies (e.g. Poehlmann *et al.*, 2005) and found to be important to the well-being of parents (Taanila *et al.*, 2002). Furthermore, Wilgosh and Scorgie (2006) argue that professionals can help to facilitate the process of choice-making by valuing parental

knowledge of their children and developing collaborative partnerships with them, in hopes of encouraging a more positive sense of their parenting.

Wilgosh and Scorgie (2006) argue that the processes of image-making, meaning-making and choice-making can result in significant changes or “transformations”. For example, they describe ways in which parents had been positively changed as a result of parenting a child with a learning disability such as: becoming stronger; realising something profound about themselves; being less judgmental; more understanding; and realising what is important in life. Various other qualitative researchers have found similar positive outcomes (e.g. Stainton & Besser, 1998; Taunt & Hastings, 2002).

Wilgosh and Scorgie (2006) stress that these questions are likely to arise throughout the child and family life cycle, requiring a reworking of images and meanings and the provision of a new range of choices. They further note that professionals who are aware that adjustment is not always a linear process are less likely to judge parents and more likely to continue to encourage positive life management and transformation. In addition, while many parents report positive transformations as described above, it has been emphasised that this is not necessarily indicative of a lack of negative outcomes. Indeed, Hastings and Taunt (2002) note that positive experiences typically co-occur with stressful experiences but that positive perceptions can be viewed as one means by which parents can cope with the challenges of raising a child with a learning disability.

#### ***1.5.5 Adjustment in families with a child with a learning disability/ASD***

There are a growing number of studies which give an insight into how both positive and negative parental adjustment and coping are influenced by a number of factors e.g. child characteristics, family or environmental features and factors relating specifically to the parent. Furthermore, various theoretical models have been proposed to conceptualise these factors e.g. the double ABCX model (McCubbin & Patterson, 1983). A full consideration of the factors associated with parental adjustment is beyond the scope of

this study. However, in terms of child characteristics related to specific dimensions of family adjustment, the following have been shown to be important: age and gender (e.g. Emerson, 2003); child behaviour problems (e.g. Hastings, 2003; Simmerman *et al.*, 2001); physical health (e.g. Neely-Barnes & Macenko, 2004); type and severity of disability (e.g. Abbeduto *et al.*, 2004); communication ability (e.g. Blacher & McIntyre, 2006); adaptive behaviour limitations (e.g. Saloviita *et al.*, 2003); and the social impact of the child's difficulties (e.g. Emerson, 2003).

In terms of parental and family factors, the following have been shown to be related to variations in adjustment: maternal age (e.g. Flynt & Wood, 1989); education level (e.g. Yau & Li-Tsang, 1999); coping strategies used by parents (e.g. Grant & Whittell, 2000); parental personality factors such as sense of coherence, self-efficacy and locus of control (e.g. Hassall *et al.*, 2005; Hastings & Brown, 2002; Olsson and Hwang, 2002). Most of this research involves only mothers, therefore there is a lack of data concerning differences between parents in adjustment. However, a strong spousal relationship (Yau & Li-Tsang, 1999), high family cohesion (Blacher *et al.*, 1997) and father participation in caregiving have been shown to influence both parents' appraisal of the burden of care and, therefore, better parental adjustment.

Clearly, the above findings are clinically important but the findings must be interpreted in light of various methodological concerns. For example, the majority of the findings are unable to determine causality between variables since most of the studies employ correlational methods and often lack control groups. A lack of longitudinal data also limits understanding of the adjustment process over time. Further concerns relate to the fact that much of the literature reviewed in this area fails to employ representative samples of families to enable the study of the broader social context within which families operate. Emerson *et al.* (2006) argue that such a failure serves to reinforce an overly 'pathological' orientation in which children with learning disabilities are implicitly assumed to be a 'burden' and a cause of parental distress. Arising from

concerns such as this, a number of studies have explored broader contextual factors that impact on a parent's ability to adjust to the diagnosis of their child e.g. low rates of employment or delayed entry into the workforce (e.g. Seltzer *et al.*, 2001); socio-economic circumstances (e.g. Emerson *et al.*, 2004); and the nature and quality of both proximal and distal forms of social support (e.g. Hatton *et al.*, 2002).

Another limitation of much of the research is that it is mainly focused on White families, thus limiting our understanding of the same issues within families of a non-White background as well as of how issues of race, culture and language affect families of children with learning disabilities.

## **1.6 Culture in the lives of families of children with a learning disability/ASD**

### **1.6.1 Introduction**

*"It is a supposition of cultural psychology that when people live in the world differently, it may be that they live in different worlds" (Shweder, 1991, p.23).*

The under-representation of non-White families in research is problematic given that a family's culture and ethnicity can have powerful influences on family beliefs, values and practices as well as how they seek and experience formal and informal support (Ferguson, 2001; Neely-Barnes & Dia, 2008). Indeed, a number of studies have shown that a parent's response and adjustment to a diagnosis of disability in their child can be profoundly shaped by cultural meanings associated with disability (e.g. Harris, 1996; Harry, 1992). In addition, there is recognition that the type and intensity of the impact of having a child with a learning disability and/or an ASD can vary depending on factors related to culture, ethnicity and language (Hatton *et al.*, 2003).

A number of researchers have carried out studies concerning issues of culture, using qualitative (e.g. Harry, 1992; Magana, 1999), quantitative (e.g. Bailey *et al.*, 1999; Rogers-

Dulan, 1998), or mixed methods (e.g. Hatton *et al.*, 2003). The majority of these studies typically concern U.S Latino, African American or Asian American (Chinese, Japanese) samples. There are a smaller but growing number of studies carried out in the UK, mainly with South Asian families. These studies have allowed key constructs to emerge that are not typically emphasised in mainstream research e.g. family religiosity has been found to be an important aspect of the lives of African American families (Rogers-Dulan, 1998), U.S. Latino families (Skinner *et al.*, 2001), and UK South Asian families (Hatton *et al.*, 2003). The construct of familism (a cultural value including interdependence among nuclear and extended family members for support) has also been found to be an important construct in U.S. Latino families (Magana, 1999). Acculturation has also been explored with U.S. Latino families and UK South Asian families, and has been defined by Berry *et al.* (2002) as the extent to which families adopt practices of the majority culture or maintain their heritage, culture and identity, and the extent to which relationships are sought with people from other ethnic groups. Blacher and Hatton (2007) argue that these constructs may be important for families across all cultural groups, but with cultural patterning in the way they are played out within families.

### **1.6.2 Distress, disadvantage and discrimination**

As well as exploring cultural constructs, the majority of studies in this area have also been concerned with assessing levels of distress and documenting the disadvantages and discrimination that families face. This literature gives a mixed picture with some between-group comparisons showing that families from ethnic minority backgrounds report fewer negative impacts than White families. For example, Valentine *et al.* (1998) compared African American and White families and found that African American families reported greater gratification and fewer burdens in the care-giving role than White families. However, Emerson *et al.* (2004) used a sample of 408 parents in the UK and showed that scoring above the threshold for psychological distress on the General Health Questionnaire-12 (Goldberg & Williams, 1988) was strongly related to South Asian ethnicity. This reflects other findings of high levels of parental distress in South

Asian communities (e.g. Chamba *et al.*, 1999; Hatton *et al.*, 1998). However, Emerson *et al.* (2004) speculate that the association between ethnicity and parental distress is mediated by socio-economic deprivation and exacerbated by the fact that South Asian parents are less likely than White parents to receive a range of formal and informal supports.

In relation to formal and informal supports, it has been shown that although support from partners or other children within the household is often found to be important (Hatton *et al.*, 2002), South Asian families with a child with learning disabilities receive less support from extended family networks compared to White families in similar circumstances (Hatton *et al.*, 1998) and receive little support from community or faith agencies, contrary to common stereotypes (Ahmad & Atkin, 1996). Ahmad and Atkin (1996) argue that stereotypical views of 'they look after their own' (and therefore have a reduced need for specialist services) are commonly found within services and they argue that this can exacerbate the invisibility of South Asian parents and reinforce the neglect they can experience from services. In addition, Shah and Sonuga-Barke (1995) found that South Asian mothers with children with learning disabilities reported higher levels of depression and anxiety associated with living in extended families and they hypothesised that this may be due, in part, to the impact of inter-generational differences and outlooks.

Indeed, Fazil *et al.* (2002) studied Pakistani and Bangladeshi parents and found themes of mothers being blamed for the disability as well as some fathers demanding a divorce following a diagnosis. Croot *et al.* (2008) noted that scrutiny from within the immediate family and also members of extended families can often be judgmental and unhelpful, resulting in mothers often isolating themselves and their child. Other reasons postulated to account for the isolation of South Asian parents with a child with a learning disability and/or an ASD include the desire to protect their *Izzat*. *Izzat* is the term used to depict family honour (Gilbert *et al.*, 2004) and for some families, an individual's disability and associated behaviours can bring shame or dishonour on the family and, consequently,



they may feel pressured to hide the learning disability. Researchers rightly argue that stigma and isolation are not confined to ethnic minority communities and that they affect people with learning disabilities and their families from all sections of the community (e.g. Coleman *et al.* 2007). Nevertheless, in some ethnic minority communities stigma may be based on specific implications e.g. the impact on marriage prospects for both the disabled child and his/her relatives. The impact of stigma has been thought of as one factor associated with the low uptake of services (Hughes, 1984).

Despite this, many South Asian parents have expressed greater unmet service needs compared to White families (Pruchno & McMullen, 2004). However, Mir *et al.* (2001) found that South Asian parents' awareness of specialist services is low and poor awareness is associated with low use of a range of formal support services e.g. short-term breaks, respite care and family support groups (Mir *et al.*, 2001). However, Blacher and Hatton (2007) stress that low use of services is also likely to be related to socio-economic position and the actual availability of services. In addition, English language proficiency seems to be crucial for gaining an awareness of and access to available service supports (Fatimilehin & Nadirshaw, 1994). Mir *et al.* (2001) argue that where formal supports for South Asian families with a child with learning disabilities are accessed, they often fail to meet family needs in terms of sensitivity to language issues, cultural values and family backgrounds. Cross *et al.* (1989) argue that this is perhaps unsurprising given that services in the UK are primarily geared towards the beliefs, values, ideas and language of the majority culture, or the White middle-class English-speaking majority.

The wider literature on ethnicity and disability shows that many parents experience a 'learned helplessness' towards services (Mir *et al.*, 2001), whereby service non-responsiveness, clinicians' minimisation of parental concerns and difficulties in communication can lead parents to feel reluctant to use services, therefore, leaving them more vulnerable to their situation (Atkin & Ahmad, 2000; Mandell *et al.*, 2002).



Furthermore, Baxter *et al.* (1990) and Ahmad (1996) argue that racist assumptions by professionals can be particularly damaging to parents. For example, misinformation and bias concerning consanguineous marriages as a cause of disability may affect professional practice and alienate families. Ahmad (1996) argues that viewing consanguinity as a cause of learning disability promotes a reductionist model of disability which places blame on parents and reinforces negative stereotypes of cultures and traditions.

Various researchers have explored the reasons why there is a common absence of a dialogue of issues of race, culture and language in services. For example, Aitken (1998) argues that clinicians may be concerned that if they explicitly acknowledge difference such as those across race and culture, this may be interpreted as racist or oppressive by parents. This may result in clinicians being led by parents on these issues rather than taking responsibility themselves. However, Aitken (1998) goes on to argue that this parent-led approach may disadvantage and silence parents who have few resources to draw on to emphasise the credibility and legitimacy of their own values and beliefs. Furthermore, Bostock and Diamond (2005) argue that an absence of an open dialogue reinforces the misperception that issues of culture, ethnicity and language have no impact on families. This relates to wider concerns about the ethnocentricity of services and, indeed, various researchers have emphasised the need for professionals to challenge ethnocentrism in service provision that can result in discrepancies in power that are to the disadvantage of particular groups, and act as a potential barrier to culturally appropriate care (e.g. Jones & Devlin, 2009).

As a result of concerns about culturally-inappropriate services, various cultural competency training programmes are available within the NHS. However, these are rarely made compulsory and are therefore usually seen as an “add-on” to practice, rather than an essential component. Moreover, concerns have been raised by Mir *et al.* (2001) that such programmes often take a “cookbook” approach to cultural competency,

resulting in de-contextualised knowledge on issues such as religious and cultural values, norms and customs. They argue that such programmes can lead to stereotypical views and inflexible approaches to service provision.

While the findings reviewed in this section are important, various concerns have been raised about the cultural competence of some of the research carried out. For example, difficulties can arise in using standardised measures cross-culturally as constructs that frame measures are not always equally applicable across cultures (Blacher & Mink, 2004). Furthermore, Magana (2000) argues that much research has concerned between-group analyses (comparisons with White families) instead of within-group analyses. She argues that this is problematic since it often carries with it the assumption that each culture ascribes to the same set of values and beliefs and can result in equating difference (where detected) with dysfunction if compared to a mainstream sample.

### **1.6.3 Ethnic minority families' experiences of receiving diagnoses**

Compared to the literature exploring White families' experiences of the process of receiving a diagnosis of a learning disability and/or an ASD for their child, there is limited literature exploring the experiences of families of an ethnic minority background. The available literature suggests that there are differences in the timing of diagnosis for ethnic minority children. For example, several studies have shown that age of diagnosis of disability was significantly younger for White children than for ethnic minority children (e.g. Mandell *et al.*, 2002). However, it is likely that a combination of the following factors are associated with this finding: a lack of access to diagnostic services; differences in socio-economic position; a lack of culturally appropriate assessments which are sensitive to cultural variations in the presenting difficulties; and the possibility of ethnic minority parents identifying and interpreting symptoms differently and at later ages than White parents (Mandell *et al.*, 2002).

Indeed, in relation to the last point made, Daley (2004) carried out qualitative research in India with 95 families of children with autism and explored parents' ideas about what constituted problem behaviour. They found that Indian parents noticed there was a problem with their child's development about 6-10 months later than White U.S. parents. Their interpretation of symptoms also varied e.g. one father saw his daughter ignoring other children as a sign of maturity, and a mother was not concerned about her 4-year-old son's lack of speech because her belief was that Indian males begin to talk later in their development.

Hatton *et al.* (2003) examined the disclosure experiences of UK South Asian parents of a child with severe learning disabilities using semi-structured interviews and found that similar to the experiences of White parents, factors that increased satisfaction with disclosure included the relay of clear information in an emotionally supportive way, along with linking the disclosure to support services. There was also evidence that parental satisfaction with the information received during the disclosure process predicted receiving greater support from formal services. Such strong relationships between the disclosure process and practical gains for parents are not commonly found in research with White families. Hatton (2002) suggests that White parents are often able to access the service system despite potentially negative experiences of the disclosure process, whilst a negatively experienced disclosure process may be a barrier against gaining formal support beyond special education for South Asian families.

Despite similar levels of satisfaction with White families, the above researchers found that good practice in disclosure was less common for parents in their study. Difficulties included the time taken to receive diagnoses and a lack of post-diagnostic support. In addition, receiving information and advice at the time of diagnosis and after diagnosis that was culturally and linguistically appropriate was shown to be lacking. Other research has shown that the methods used to disclose diagnoses can be poor e.g. using non-professional interpreters (Butt & Mirza, 1996). However, in a similar way to White

families, Hatton *et al.* (2003) found that good practice in disclosure seemed to assist parents in meaning-making and acceptance, and practical challenges. Parents in this study reported that the disclosure had a significant impact on their understanding of their child's condition and, consequently, their emotional acceptance of their child. A lack of shared parental understanding and acceptance was found to lead to considerable parental distress, emotionally unsupportive relationships between partners, and a lack of mobilisation of informal and formal support systems.

#### **1.6.4 Responses to and understanding of a diagnosis of learning disability/ASD**

Cultural and ethnic influences on familial responses to a person with learning disabilities have been much discussed and often assumed (Reading, 1999), but there is little research to back up the assumptions. The research that exists presents an inconclusive picture. It is worth noting from the outset that many similarities are found across cultural groups in parental reactions to their child's diagnosis, including the most common parental reaction of love for their child (Mary, 1990). Indeed, while the positive aspects of caring for a child with a learning disability and the coping resources of families are being increasingly examined in White families, little research with ethnic minority families has taken this approach. However, the little research that exists suggests that cultural context is important in the assessment of positive outcomes in learning disability for U.S. Latino mothers (e.g. Blacher & Baker, 2007).

Various studies have been carried out investigating South Asian parents' perception of their child and their disability. Some have reported that parents view the learning disability as the will of God and their role as a parent as a pious act or test of faith (e.g. Mirza *et al.*, 2009). Others have reported it as being a gift from God (Croot *et al.*, 2008). Still others have reported that parents may believe they are being punished for their sins, and therefore feel guilty and passive (Stubblefield, 1977). It has been suggested that such theological beliefs may help to provide parents with an understanding of what has

happened that can either lead to a sense of acceptance or resignation and low expectations of their children and their future (Webb-Johnson, 1991).

Bywaters *et al.* (2003) carried out semi-structured interviews with 19 South Asian families exploring parental attitudes and understandings of disability and suggested that theological explanations for disability were more likely to be adhered to when parents were not given adequate information about cause of disability from health professionals. They refuted the suggestion that religious beliefs in South Asian families lead to passive and negative attitudes to disability and subsequent poor uptake of services, suggesting instead that practical and material barriers prevent access. Furthermore, other research has found that South Asian parents often seek out explanations of disability pertaining to both theology and medicine, demonstrating that they are not mutually exclusive (e.g. Croot *et al.*, 2008; Fatimilehin and Nadirshaw, 1994). In addition, Bywaters *et al.* (2003) suggested that parents are much more likely to accommodate alternative views concerning their child's disability when their own culturally and religiously-embedded views are respected and acknowledged, rather than dismissed (Bywaters *et al.*, 2003). Furthermore, it has been shown that when South Asian parents have a good understanding of the medical explanation of their child's disability, they appeared to use this to refute negative ideas when family members expressed unhelpful beliefs about the causes of their child's disability and a hope for a 'cure' (Hatton *et al.*, 2003).

Indeed, various researchers have found that South Asian parents and their extended families are often more poorly informed about learning disability than White British families. For example, a study by Channabasavanna *et al.* (1985) listed some misconceptions that South Asian parents had about learning disability. These included the notion of curability, and that marriage of a person with a learning disability may alleviate the 'condition'. Research carried out by Coleman *et al.* (2007) also reflects ethnic minority parents' hopes for a cure. The authors note that it is unlikely that such hopes

are confined to ethnic minority parents, but that in the midst of experiences of discrimination, such hopes may well enable parents to cope.

### **1.7 Summary of research area and aim of current research**

It is now well known that disclosure of a child's diagnosis is a crucial period for White parents with a child with a disability (Quine & Pahl, 1987; Sloper & Turner, 1993). Good practice in disclosure has found to be associated with parental understanding of their child and mobilisation of methods for coping, and subsequent adjustment (Sloper & Turner, 1993). However, very little research has focused on how South Asian parents experience the disclosure of diagnosis, how they come to understand the diagnosis and subsequently adjust to it.

Therefore, the present study seeks to build on the small body of existing cross-cultural research in this area by exploring South Asian parents' experiences of the diagnostic process for their child and the factors that may influence their subsequent understanding, acceptance and adjustment of the diagnosis and their child. In addition, since so little is known about positive experiences and outcomes for South Asian families with a child with a disability, the present study aims to draw out positive themes while exploring the above areas.

Since this is a qualitative study which aims to investigate the above issues in an open and explorative way, there are no pre-existing hypotheses to be tested.

It is hoped that the results will contribute to a greater understanding of whether there is cultural, ethnic or religious patterning in the way that South Asian parents experience the disclosure of diagnosis for their child and in their post-disclosure understanding, acceptance and adjustment. Furthermore, the author hopes to improve clinicians' knowledge in this area as well as give suggestions about how they can better meet the

needs of South Asian families during the crucial times of disclosure of diagnosis and post-disclosure.

## CHAPTER 2      METHODOLOGY

### 2.1      Methods of cross-cultural research

Hatton (2004) describes various research paradigms arising from Berry's work on three theoretical orientations within cross-cultural psychological research (Berry, 1999). Firstly, *absolutism* assumes that human phenomena are basically the same across all cultures. Thus, culture is assumed to play little or no role in either the meaning or display of human characteristics, with biology or economic circumstances usually assumed to underpin cross-cultural differences (Hatton, 2004). Helman (2000) says that with this view, the use of concepts such as "depression" across cultures, along with the use of (translated) standardised measures, is assumed to be unproblematic.

In contrast to the absolutist approach is *relativism*, which assumes that all human behaviour is culturally determined i.e. each culture is unique and, therefore, cannot be compared with other cultures. It follows that each culture must then be understood "on its own terms" (often called an *emic* approach; Hatton, 2004). According to this approach, Hatton (2004) notes that cross-cultural comparisons are theoretically indefensible and inevitably ethnocentric, and therefore, attempts to look for cross-cultural universals should not be made.

Lastly, *universalism* assumes that basic human characteristics are universal, and that culture influences the development and display of these characteristics. The degree to which particular characteristics and behaviours are cross-culturally universal or culturally patterned will vary, and can be tested empirically (often called an *etic* approach). Hatton (2004) states that one of the aims of universalist research is to determine the cross-cultural equivalence of the constructs existing within a particular theoretical framework (e.g. stress, coping, social support) and to develop corresponding cross-cultural equivalent measures.



Hatton (2004) says that the vast majority of the research in the field of learning disabilities has implicitly taken an absolutist stance, with a result of the majority of constructs, measures, and theories being developed with reference only to the culture of the researchers (typically White). Furthermore, he states that very little, if any, research has been carried out which adopts a relativist position since according to this paradigm, researchers cannot even engage in emic research with other cultural groups from themselves, as this involves a “de facto imposition of the researcher’s cultural worldview on another cultural group” (Hatton, 2004; p. 46).

Given the limitations in the above two approaches, the present study aims to take a universalist approach. Berry (1999) proposes a set of research strategies to underpin a universalist paradigm including: transporting and testing current psychological knowledge and perspectives by using them in other cultures; exploring and discovering new aspects of the phenomenon being studied in local cultural terms; and integrating what has been learned from the first two strategies to generate theories of cross-cultural applicability which are testable.

Hatton (2004) suggests that a universalist paradigm offers the best way forward for research investigating the role of culture in the lives of families of people with a learning disability. Therefore, the present study adopts a universalist stance to examine the experiences of South Asian parents of receiving a diagnosis of a learning disability and/or an ASD and subsequent adjustment.

## **2.2 Research strategies underpinning universalism**

Emic research strategies aim to build up a detailed picture of a culture on its own terms in order to establish constructs, measures and theories grounded within the experience of a culture. There have been a number of examples of emic research such as Magana’s (2000) research concerning people with learning disabilities in US Latino communities and Hatton *et al’s.*, (2003) research with UK South Asian families with a child with

severe disabilities. Etic research is more concerned with investigating the cross-cultural applicability of constructs, theories and measures which have been derived from emic research. Hatton (2004) states that the majority of etic research is usually conducted quantitatively. Consequently, it follows that the present research is best met by undertaking research which is emic in nature. Hatton (2004) states that emic research lends itself well to qualitative approaches, as such approaches are specifically designed to build accounts or hypotheses grounded in the data obtained, whilst minimising the preconceptions researchers bring to the study in obtaining, recording and analysing data.

### **2.3 Justification for a qualitative approach**

Epistemology examines the legitimacy of various types of knowledge and highlights the fact that there are disagreements about the unanimity of research methods (Cutcliffe, 2000; Morse, 1999a, 1999b; Whittemore *et al.*, 2001). The underlying epistemology of qualitative research has been described by Henwood & Pidgeon (1992) as naturalistic, contextual and interpretative. This is in contrast to the opposing epistemological position underlying quantitative approaches i.e. experimental, hypothetico-deductive and positivist (Henwood & Pidgeon, 1992).

Qualitative research is concerned with human meaning, experience and consciousness. Fourie (2008) notes that since these are complex, non-linear and multi-factorial they lend themselves well to research using a qualitative approach. Indeed, attempts to impose quantification on human meaning, experience and consciousness have been criticised by a number of researchers (e.g. Henwood & Pidgeon, 1992) on the grounds that it is unrealistic to explore subjective meaning with externally structured quantifications since this results in a reductionist view of such complex phenomena and, therefore, masks the fact that human meaning is unique and variable according to context. Furthermore, positivism and hypo-deductivism have been criticised due to the requirement for researchers to be objective reporters without personal involvement. This passive and

unbiased positioning of researchers has been questioned due to its implicit assumption that data can be separated from a researcher's values, beliefs and assumptions (Charmaz, 2006).

In contrast, qualitative research involves the researcher becoming an "active participant" in the research process by immersing herself in the social world of participants and, thus, being more able to understand and interpret the meanings attributed to their experiences. Maxwell (1996) has noted that qualitative research is especially valuable when a researcher seeks to understand how participants make sense of events and objects and to examine processes which change over time and context.

#### **2.4 The use of a qualitative approach for the current study**

In addition to Hatton's (2004) recommendation that emic research lends itself particularly well to qualitative research, the researcher felt that a qualitative approach also fits particularly well with the present study since it provides the opportunity for a disenfranchised and often invisible group to be heard. In addition, Patel (1998) states that qualitative methodologies generally lend themselves well to an exploration of sensitive topics within their relevant socio-political contexts. One such qualitative methodology is Grounded theory, which is the method applied in the current study.

#### **2.5 An overview of Grounded Theory**

Grounded theory was first described by Glaser & Strauss (1967) more than 40 years ago and is now the most widely used qualitative research method (Charmaz, 2006). Grounded theory has been used in a range of disciplines to study a wide range of subject areas e.g. terminally ill patients' awareness of dying (Glaser & Strauss, 1965); speech and language therapy (David & Whitehouse, 1998; Fourie, 2008; Nettleton & Reilly, 1998); occupational therapy (Stanley & Cheek, 2003; Tamm, 1999; Whitcher & Tse, 2004); and management (Kan & Parry, 2004; Mohr, 1996). However, Dallos & Vetere (2005) view

grounded theory approaches as being particularly well suited to psychotherapy-based research due to their ability to let participants' accounts speak for themselves.

Fourie (2008) suggests that the use of grounded theory in such wide ranging areas traditionally served by quantitative approaches is likely to be due to its ability to develop plausible theories for complex systems. Indeed, grounded theory was introduced not as an attempt to test theories but rather as a comprehensive and systematic way to develop and build theory (Dallos & Vetere, 2005). Grounded theory involves systematic data collection and analysis procedures in order to arrive at a theory which is 'grounded' in the data (Glaser & Strauss, 1967). Most grounded theory studies arrive at an initial substantive theory but can be developed into more abstract formal theory. This can be achieved by including materials from other studies, re-analysing the original material (Glaser & Strauss, 1967), and investigating a phenomenon under varying conditions and situations (Strauss & Corbin, 1990).

Theoretical sampling is one of the key procedures underpinning a grounded theory approach (Charmaz, 2006). It involves seeking new data when the emerging theory directs that a new area be explored further e.g. purposively selecting new participants on the basis that their narrative may help to develop the growing concept or to refine ideas (Barker *et al.*, 2002; Strauss & Corbin, 1998). The grounded theory is then refined by searching for differences and similarities between subsequent interviews. For this to happen, all interview data must be 'coded' and analysed during the data collection stage.

The coding process involves fragmenting data into individual lines, sentences or units of meaning and then naming each segment of data with a category label. Willig (2001) states that categories can initially function as descriptive levels but as analysis progresses, they become more interpretative and analytic. Charmaz (2006) advocates the use of 'in-vivo' category naming and describes this as labels which mirror the words or

phrases used by participants. This is said to minimise the influence of existing theory and preconceptions held by the participant. At the same time, the influence of the researcher's previous knowledge and understanding of the phenomenon being studied is explicitly acknowledged.

The process of 'constant comparison' follows coding and involves comparing each piece of data with the other and with emerging categories and theories. This leads to the potential identification of sub-categories. The data collection phase of the project stops when no new information or categories are found. This is known as 'theoretical saturation' (Glaser & Strauss, 1967).

The use of 'memos' is a key process in grounded theory throughout coding and analysis. Memos are records of a researcher's ideas and emotional reactions to the data and emerging categories (Dallos & Vetere, 2005). A key function of memos is also to focus on the relationships between codes and categories (Boychuk *et al.*, 2004). The process of creating memos is thought to facilitate theoretical sampling and hence the development of theory (Glaser & Strauss, 1967). Producing memos allows the researcher to keep a record of the theory generation process and requires an ability to think reflexively.

A core category has a number of properties. Glaser (1978) states that a core category can be any type of theoretical code such as a process, a dimension or a consequence which is central to theory, is recurrent in the data, is not easily saturated, has rich interconnections with other categories, has clear implications for theory and is completely variable. Following analysis, categories are sorted and integrated together to provide an explanatory framework for the phenomenon under study (Charmaz, 2006). The resulting theory is often presented in the form of a diagram as a way to provide a visual representation of the relationships between categories.

Strauss & Corbin (1990) suggest that the quality of a grounded theory study can be ascertained by considering, for example, the coherence of categories/theory and the significance of theoretical findings.

## **2.6 Justification for the choice of Grounded Theory in the current study**

While a grounded theory approach was adopted in the current study, the researcher acknowledges the availability of other qualitative methods. Two other methods considered were content analysis and Interpretative Phenomenological Analysis (IPA). Content analysis was not chosen because of its tendency to impose an already existing conceptual framework on data. In addition, Manning & Cullum-Swan (1994) argue that content analysis is “microinteractional” in aspect due to its tendency not to take into account the meanings of experiences for participants and, furthermore, its tendency to neglect the variability and context-dependent nature of meanings. In addition, unlike grounded theory, content analysis does not aim for theory generation.

Grounded theory as opposed to IPA was chosen because the former facilitates the development of a ‘middle-range theory’ which is grounded in a foundation of systematically analysed data (Charmaz, 2006), whereas IPA facilitates the development of a more local theory. In addition, the more explorative nature of analysis in grounded theory compared to the need to be interpretative from the beginning of analysis in IPA helps the researcher to avoid forcing data into preconceived categories. Connor (2005) states that this becomes even more important when the researcher holds pre-existing knowledge in the area and also when the researcher and participants share similar backgrounds or have shared similar life experiences.

In summary, the main reason that grounded theory was chosen was because of a desire to develop theory which is grounded in the data and which explicitly examines the meaning of experiences to participants. It was also chosen due to its emphasis on the context-dependent nature of these experiences. A grounded theory approach was felt to

be important particularly when exploring an under-researched area where the majority of the studies available, although providing interesting findings, usually lack a theoretical basis (Hatton, 2004).

## **2.7 Constructivist Grounded Theory**

Whilst adopting a grounded theory methodology, the current study takes a constructivist stance (Charmaz, 2003a). This allows the identification of the researcher's stance as a participant in the research process by acknowledging pre-existing knowledge of the area being explored, as opposed to the stance of an unbiased and distant observer. In addition, it explicitly acknowledges the relationship between the researcher and the participants and the collaboration between them in the process of generating data. As such, in the present study the researcher kept a research journal throughout the entire process of the study in order to document her experiences of carrying out the interviews and analysing the data, as well as fostering her reflexivity about her own interpretations as well as those of participants. The main themes arising from the journal entries are discussed later in this report.

Constructivist grounded theory emphasises that participants' narratives are shaped by social, cultural and historical contexts as well as being shaped by how the participant believes the researcher and other participants will interpret the narrative. Charmaz (2003a; p.275) says that in this way, constructivist grounded theory is 'a form of inquiry that closely resembles the real world of participants as it aims to include multiple voices, views and visions in the rendering of lived experience'.

For the above reasons the researcher felt that constructivist grounded theory fits particularly well with emic research especially since one of its focuses includes an acknowledgement of the role of culture and other contexts on an individual. Furthermore, its emphasis on multiple realities resonated with the researcher due to the fact that South Asian communities are often assumed to be a homogenous group but the



researcher's understanding is that this is not the case. Therefore, she expected there to be a diversity of views associated with South Asian parents' experiences.

## **2.8 Use of Grounded Theory in the current study**

### **2.8.1 Introduction**

The researcher aimed to develop a theory of the experiences of South Asian parents in relation to receiving diagnoses of a learning disability and/or an ASD for their child. In doing so, she hoped to investigate how cultural factors may impact on the way that these diagnoses are given and received as well as how parents subsequently come to adjust to the diagnosis. Accordingly, the researcher interviewed seven adults with a child or adolescent with a diagnosed learning disability and/or an ASD. This was achieved by using a semi-structured interview methodology and carrying out analysis of transcribed interviews using grounded theory methods.

### **2.8.2 Ethical issues**

Ethical approval to carry out the interviews with parents was sought and obtained from the Lothian NHS ethics panel. They considered this to be an appropriate research project (Appendix 1).

The researcher considered a number of ethical considerations before commencing the study. Possible ethical issues e.g. child protection concerns were discussed with the researcher's clinical supervisor before data collection commenced, and strategies for managing these were agreed. It was essential that the researcher obtained the informed consent of the participants. Therefore, the researcher conveyed the nature, duration and purpose of the study in unambiguous and clear terms by producing an information leaflet (Appendix 2). This was read out to participants who were also given a paper copy to keep. Participants were also asked to sign a letter of consent, asserting their agreement to participate in the study (Appendix 3).



For those who consented to take part, procedural considerations were clarified with each participant before the interviews commenced. These included how confidentiality would be ensured, how interview recordings and transcripts would be managed and the opportunity to ask further questions. This study was informed by the guidelines set out in the British Psychological Society Code of Conduct, Ethical Principles and Guidelines (British Psychological Society, 2000b).

### **2.8.3 Participant selection**

Qualitative methodology advocates the use of small, but purposive samples. As a result, populations are rarely random but recruited as they belong to a particular social group, or have experienced the phenomenon under investigation. Therefore, the following inclusion and exclusion criteria were used to find suitable participants:

#### **2.8.3.1 Inclusion criteria**

Participants had to be: adults who were of a South Asian background i.e. first or second generation Pakistani, Indian or Bangladeshi; parents of a child or an adolescent with a diagnosis of a learning disability and/or an ASD; and willing to be interviewed.

#### **2.8.3.2 Exclusion criteria**

Participants could not be: at an early stage of contact with services in relation to receiving a diagnosis (in order to prevent any disruptions to the development of a therapeutic relationship with the service involved); experiencing an acute phase of mental health/psychiatric difficulty; or unwilling to use an interpreter if they were not able to converse in English.

### **2.8.4 Characteristics of participants**

In total seven parents were interviewed, five of whom were female and two of whom were male. All participants were of a Pakistani background (three second generation and four first generation) and all participants identified themselves as being Muslims. The majority of participants had been educated to high school level and three had

completed higher education degrees. The age range of parents was 27 to 52 years old and the age range of children was 6 years to 12 years old. All children had a learning disability and five also had a diagnosis of autism. One child had a diagnosis of Down's Syndrome in addition to autism and a learning disability. All participants in the study met the inclusion and exclusion criteria.

A table summarising the characteristics of the participants can be found in Appendix 4.

### **2.8.5 Research context**

Drapeau (2002) states that it is important to have information regarding the context in which a qualitative study is conducted in order to gain further insight and to limit potential biases. The researcher was carrying out her final placement in a Child and Adolescent Mental Health Service (CAMHS) for children and young people with learning disabilities and/or autism in Lothian. This team is comprised of clinical psychology and psychiatry professionals. The team covers a wide geographical area and accepts referrals for children and young people aged 0-16 inclusive who have a moderate to severe level of learning disability and/or autism and who have additional sensory issues, emotional, behavioural and/or psychiatric difficulties. The team has close working relationships with Community Learning Disability Nurses (CLDNs).

The researcher anticipated being able to recruit most of the required number of participants from CAMHS and the CLDNs. However, she was only able to recruit two participants in this way. Once the first interview was completed, the researcher used a snowballing recruitment technique and was informed of a voluntary organisation in Edinburgh who held monthly support meetings for Black and Ethnic minority parents who have children with learning disabilities. The researcher attended one of these meetings in order to inform attendees about the nature and purpose of the study. Five parents in the group expressed an interest in participating.

All participants were given a choice about where the interviews were held and all opted for them to be carried out at their homes. Charmaz (2003b) argues that interviews carried out in home settings allows for a more 'naturalistic' setting in which participants can recount their experiences.

The following section provides greater detail about the recruitment process.

#### **2.8.6 Recruitment process**

Prior to commencing data collection, the researcher met the Lothian Child and Adolescent Mental Health Learning Disability team to discuss the purpose of the study as well as to discuss the proposed format for the interviews. The information sheet was circulated to all team members who were given the opportunity to raise any queries or concerns about the study. The researcher also contacted all CLDNs in Lothian to inform them about the nature and purpose of the study.

The researcher subsequently contacted team members individually to enquire whether they had any potential participants who met the inclusion criteria. If they had potential participants the researcher and clinician discussed the best way of informing them of the study and gaining consent for participation. It was decided that the first contact with potential participants would come from the clinician they were working with, either by telephone or at their next scheduled clinical appointment. It was agreed that clinicians would go over the information sheet and give the opportunity for any concerns to be discussed about participating. If participants expressed an interest in taking part in the study, there were two potential options open to them:

- Attend a parent group. The aim of this group was to allow potential participants to meet with the researcher to discuss the study in more detail. The rationale for providing this in a group context was to allow a greater number of potential participants to be met at one time; or

- meet with the researcher individually to obtain further information.

All participants felt that attendance at the parent group was unnecessary and all were able to provide consent after an initial discussion with the researcher. The researcher arranged interviews to take place no less than 72 hours later than the initial discussion to allow participants a 'cooling off' period which gave them time to re-consider their participation and if necessary, withdraw their consent.

### **2.8.7 Pilot interview**

A pilot interview was not carried out with a research participant given the already small pool of potential participants to recruit from for the main data collection. Instead, the researcher was able to test out the relevance and appropriateness of the interview schedule (Appendix 5) with her clinical supervisor as well as with another trainee clinical psychologist who had experience in data collection for qualitative studies. Both were able to suggest minor modifications to the wording of questions as well as suggesting other questions to explore in order to gather more detailed information. Practising in this way enabled the researcher to practice and refine the style needed for qualitative interviews.

### **2.8.8 Interview format**

All interviews began with questions relating to parental characteristics (e.g. age and education level), family characteristics (e.g. languages spoken and religion) and child circumstances (e.g. age, gender and diagnoses). This information has already been discussed and can be found in Appendix 4.

Each participant was then asked the standard question of: "Can you tell me when you first noticed your child had difficulties?". This opened up the interview to the area of research and allowed further questioning related to experiences of the process of receiving a diagnosis for their child, how they came to understand their child's

difficulties and factors which may have impacted upon this. The style of interview followed the format of qualitative interviewing, which encourages the description of the details of events and the exploration of their meaning to the individual (Charmaz, 2006; Rubin & Rubin, 1995). The researcher felt that the style of interviewing helped interviewees to describe their experiences in detail, to gain an understanding of the meaning of those experiences for the individual, and to gain an impression of whether, and how their thoughts and feelings about their experiences had changed over time. The researcher frequently summarised information obtained to check its accuracy as well as to convey the message that participants were being heard. The researcher attempted to use the terminology of the participants and ensured to check out the meaning of idioms and certain cultural and religious phrases that were unknown to her.

Interviews were spaced out as far as possible within the limited time frame in order to allow the researcher to familiarise herself with the data obtained before the next interview occurred. In line with a grounded theory approach, the content of the interviews evolved as the research progressed in line with the method of theoretical sampling. In addition, the researcher considered possible areas that could arise in the interviews but only explored these if the participant initiated or responded to them. The initial four interviews were kept as open as possible and the participants were encouraged to direct them. Later interviews became more focussed on particular themes that had emerged. This was shared with the participants who were informed that the researcher may ask them to comment on their experience in comparison to what other participants had already expressed.

While collecting data, the researcher had a number of practical issues to keep in mind. For example, certain parents expressed preferences for particular times of the day to undertake the interview so as to not clash with prayer times. In addition, one parent explained that while her proficiency with the English language did not merit the use of an interpreter, she explained that she would require longer to respond in English. The

researcher was required to word her questions even more carefully with this participant, not assuming, for example, an understanding of constructs such as “adjustment” which might not have been familiar to her.

#### **2.8.9 Data management**

All interviews were recorded with a digital recorder. Before commencing the interviews, participants were given an explanation about the purpose of recording the content of the interview. After the interviews, recordings were stored on a computer and erased from the digital recorder. Each interview was then transcribed verbatim. Any identifiable information was either deleted or changed to ensure anonymity.

The researcher was aware that there are various software packages which can be used to store and organise qualitative data e.g. NVivo 8 (QSR, 2008) and Atlas Ti (Muhr, 1997). However, the researcher decided not to use any software due to the limited time-frame available in which to feel confident in using such packages. In addition, the researcher was aware of concerns summarised by Bazeley (2007) that the use of computers can distance researchers from their data, potentially resulting in a ‘mechanistic’ approach to analysis and, thus, ‘making it more akin to quantitative or positivist approaches’ (Bazeley, 2007, p.8).

#### **2.8.10 Data Analysis**

As each transcript was completed, the researcher read the material several times, resisting the urge to begin the process of coding. The researcher felt that this allowed her to become immersed in participants’ accounts of their experiences. The researcher then began the first stage of analysis of line-by-line coding. It was not uncommon for each line to have several codes attached to it (Appendix 6 contains an extract of a coded transcript). In-vivo codes were used wherever appropriate. The researcher began to record memos at the beginning of the coding process and continued to do so throughout the remaining data analysis.

Following initial coding which resulted in distinct codes, the researcher undertook further coding to specify the properties and dimensions of the main categories. This involved sorting and synthesising the initial codes obtained. At this point, coding became more interpretative and analysis involved thinking theoretically about the relationships between categories. The process of constant comparison of codes resulted in previously identified categories being grouped together if they were conceptually similar (and renamed if appropriate). Thematic categories were introduced into the later interviews to enable theoretical sampling. This allowed core categories to be identified. The constant comparison of data continued so that links between categories could become clearer. Following the completion and analysis of seven interviews, theoretical saturation was deemed to be sufficient for the purposes of the study within the time-frame available. It should be noted that the researcher was aiming for 'theoretical sufficiency' (Dey, 1999) rather than total saturation, as this is deemed to be impractical in small studies conducted within a limited time-frame (McCallin, 2003). This issue is discussed in further detail in Chapter 4.

Following the completion and analysis of all interviews, the categories and memos were sorted into a structure which seemed to represent and clarify the theoretical relationships identified. At this time, there was a return to relevant literature in order to explore material which could help to further develop and validate the emerging theory.

## **2.9 Ensuring quality in qualitative research**

### **2.9.1 Introduction**

Reliability, validity and generalisability are widely recognised as being some of the main criteria for establishing rigour in positivist research. However, in their true positivist sense they aren't applicable when conducting research which is contextual, interpretative and naturalistic (Janesick, 2003). However, reliability and validity remain intrinsic to the grounded theory approach and a number of researchers have outlined





various ways in which quality can be ensured in a grounded theory study (e.g. Lincoln & Guba, 1985; Willig, 2001). The next section outlines the various ways in which the current study took steps to ensure quality.

### **2.9.2 *Triangulation***

Triangulation of methods refers to the seeking of information from multiple sources, methods and interpretations. Lincoln & Guba (1985) state that triangulation is one way of ensuring that research findings are credible. Dallos and Vetere (2005, p. 205) further state that “triangulation as a strategy is based on the idea that different perspectives on the same phenomenon can enhance our understanding”.

In order to allow triangulation to occur, discussions were held with both clinical and academic supervisors throughout the research process. The clinical supervisor was a Clinical Psychologist who has expertise in working with children with learning disabilities and their families and the academic supervisor has expertise in using qualitative methods. Both supervisors reviewed samples of coded transcripts and there appeared to be good agreement in relation to the coding and the categories being proposed by the researcher. Any differences in opinion were acknowledged and incorporated into the analysis process where appropriate. Both supervisors also provided input at stages where the model was being developed.

In addition, the researcher was part of a small qualitative supervision group made up of trainee clinical psychologists who were undertaking qualitative research. In this group, several random samples of transcripts were exchanged and comments made on the coding used. This served as a further way to gain other perspectives on the data and to limit potential biases in interpretation. Triangulation was also carried out by referring to existing literature as categories were developed. This is demonstrated in later chapters, where literature is reviewed in relation to the core categories. Lincoln and Guba (1985)



state that in addition to triangulation methods, the credibility of qualitative research findings can be assessed by undertaking member checks.

### **2.9.3 *Member checks***

It was important to assess whether research findings accurately represented the views of participants. Lincoln & Guba (1985) say that since the researcher is attempting to describe phenomena from the viewpoint of participants, it is important that participants judge the credibility of findings. In the current study, member checks were carried out at various stages. Important themes arising from initial interviews were fed back to participants in subsequent interviews. Member checks were also conducted after completion of data analysis with two participants who agreed to take part in the final member check. This allowed the researcher to discuss her interpretation of participants' accounts and to allow an opportunity for them to make comments. Strauss and Corbin (1998) highlight that although a grounded theory may not fit every aspect of participants' experiences, the higher-level concepts should be applicable and recognised by them. Both participants felt that the proposed model represented their experiences well. This is discussed in further detail in chapter 4.

Finally, the researcher used member checks to assess the possibility of cultural bias operating in the data collection and analysis. This involved, for example, ensuring that her preconceptions and knowledge of constructs and theories drawn from other cultures had not unduly influenced the process of the research (Hatton, 2004).

### **2.9.4 *Transferability of research findings***

Lincoln & Guba (1985) state that the extent to which findings can be applied to other contexts is an important issue to consider in assessing the quality of a qualitative study. They go on to state that the 'transferability' of research findings can be enhanced in a number of ways. For example, the research context was explicitly detailed allowing readers to be aware of the context in which the research was conducted, thereby

increasing transparency and the ability for research findings to be 'transferred' to similar studies. Lincoln & Guba (1985) also argue that the use of richly described data provides the reader with sufficient information necessary to judge the extent to which findings can apply to other people in other settings.

#### **2.9.5 Dependability of research findings**

Dependability of research findings relates to their reliability i.e. the extent to which if the inquiry 'were replicated with the same or similar respondents in the same context, its findings would be repeated' (Erlandson *et al.*, 1993, p. 33). The researcher made use of an audit trail to improve the dependability of findings. This involved systematically recording the development of the analysis by documenting transcripts, chronological versions of coding and memo notes.

#### **2.9.6 Reflexivity**

The final area in which the researcher attempted to ensure quality in the current study was in relation to adopting a reflexive stance throughout the entire process of the research. Hall & Callery (2001) have highlighted that reflexivity should be used by grounded theorists in order to improve rigour and in order to enhance the transparency, accountability and general trustworthiness of qualitative research.

For the researcher, this included critically evaluating the nature of her prior assumptions and knowledge, her reactions and interpretations of data collected, how she judged the relevance of data to the research focus and how she presented herself to participants. Mishler (1986) states that these are all elements that contribute to the shaping of research findings. Given that the researcher adopted a constructivist grounded theory approach in the current study, it was of paramount importance to acknowledge the mutual role of both the participants and researcher in creating a core concept.

To aid the process of reflexivity, the researcher maintained a research journal. Amongst other things this acknowledged the researcher's pre-existing knowledge, opinions and beliefs in the area as well as ideas as to the data that the participants might generate. An extract from the research journal can be found in Appendix 7 (this has been written in the first person to reflect the language used in the journal).

## **CHAPTER 3      RESULTS**

### **3.1      Development of the model**

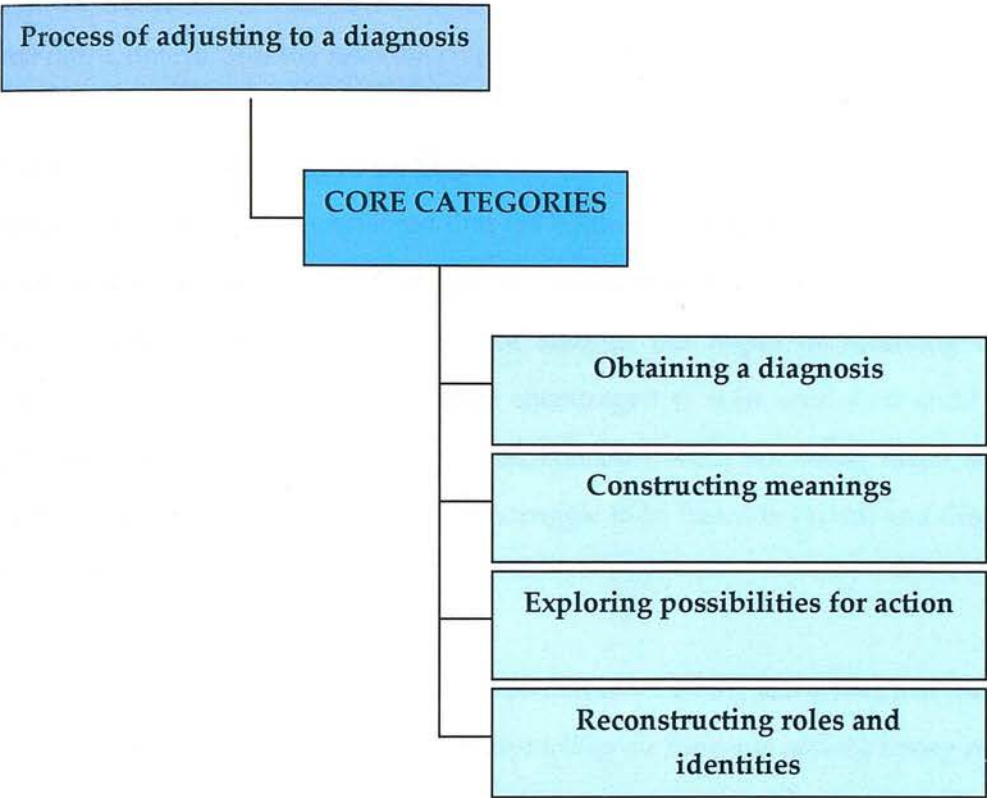
The analysis revealed that although participants spoke about their experiences in relation to the diagnostic process, much more information was given about their experiences post-diagnosis, in terms of not only their experience of formal and informal post-diagnostic supports but also how they came to accept and adjust to the diagnosis. Therefore, later interviews became more focused on the process of adjustment. The researcher felt that the complexity of the process of adjustment is hard to capture by quantitative research and, therefore, felt that exploring this in more detail in the current study would be interesting, especially when embedded within the various contextual factors that participants highlighted as having important impacts on their ability to adjust.

### **3.2      Descriptive results**

#### **3.2.1      Overview of categories**

Based on interview material, four core categories emerged. The following figure provides an overview of these categories:

Figure 3.1      *Core categories generated*



A description of the core categories will be provided with reference to direct quotes from individual transcripts as well discussing them in relation to relevant literature. Following the descriptive results, the researcher will outline a hypothesised model to account for the relationships between the core categories.

**3.2.1.1      Obtaining a diagnosis**

The core category of ‘obtaining a diagnosis’ was subsumed into three sub-categories. These are outlined in Appendix 8.

### 3.2.1.1.1 Sub-category 'Battling for a diagnosis'

Most participants described the process of seeking a diagnosis for their child as a "battle". This sub-category is comprised of three themes: struggling to be heard; tolerating delays; and the emotional strain of the battle.

#### 3.2.1.1.1.1 *Struggling to be heard*

Most of the participants explained that the battle for a diagnosis for their child often left them struggling to be heard. Some parents had repeatedly visited their G.P or discussed their concerns with nursery or school staff in the hopes of receiving a specialist assessment. However, they were often encouraged to wait until their child was older. This left some parents feeling that their concerns were not being taken seriously. In addition, certain parents attributed the struggle to be heard to racism and discrimination in service provision.

*"I kept on and on at my G.P. I told him I knew something was wrong and wanted someone to assess my child. He just kept telling me there was nothing wrong and it was just that my child was slower than other children. I felt like they were labeling me as an attention-seeking mum and that I was the one with problems"* (Participant 4).

*"Not one person I spoke to wanted to admit my son had problems with his development. My wife and I felt ignored...They look at my background and think we don't know anything...they think we are stupid, uneducated people"* (Participant 3).

*"I told the health visitor again and again I had concerns. She wasn't helpful at all, she didn't tell us about specialist assessments or services...sometimes I thought she might be a bit racist"* (Participant 1).

Struggling to be heard was also exacerbated by language and communication difficulties in one parent:

*“My English isn’t very good...and it gets worst when I’m nervous...so it was hard to get across what my concerns were...hard to be understood. An interpreter would be good but no-one gave me this” (Participant 6).*

While the above quotes illustrate parents’ difficulties in having their concerns listened to and understood, one parent spoke about her experiences of being positively supported by her child’s school to receive a specialist assessment for autism.

*“I didn’t know what autism was before my son started school. They spoke to me early on and told me they had some concerns about him and that they would make a referral to get an assessment...I’m glad they did cos I probably wouldn’t have started to notice there were problems till he was older” (Participant 5).*

#### **3.2.1.1.1.2 Tolerating delays**

Most parents explained that they felt there was a significant gap between noting their first concerns about their child’s development and finally receiving a diagnosis. Their struggle to be heard invariably continued throughout this time. There was a general consensus that receiving an earlier diagnosis would have been beneficial in terms of receiving appropriate supports for their child.

*“My son’s diagnosis was very late. I feel if they had listened to me earlier we could have gotten the right supports in place earlier. The delay could have held him back even more, I don’t know” (Participant 1).*

*"My son had a diagnosis of global developmental delay till he was 10...I didn't feel that was right, it didn't really tell us anything about him...I knew there was more to it but we had to wait till he was 10 to get a diagnosis of autism" (Participant 6).*

*"I had to wait a long time to get a diagnosis. It was very frustrating because without a diagnosis, a label, you can't get the supports your child needs. So you are just left waiting, knowing you could be helping your child more but feeling constrained by not having a diagnosis" (Participant 4).*

#### **3.2.1.1.1.3    *Feeling the strain of the battle***

Parents spoke about the emotional impact of battling for a diagnosis. The struggle to be heard and the effects of lengthy delays left parents feeling a range of emotions, including frustration, helplessness, confusion, low mood and worry. Some parents felt they were letting their children down by not having a clear understanding of their needs and, therefore, how to help them. This was related to feelings of self-blame and guilt.

*"It was a horrible time because I would look at my child and not really know what was going on for him. I knew he had difficulties but not having a clear understanding of them made things really hard for me...I felt guilty, I should have known how to help him but without professional help I was a bit lost" (Participant 1).*

*"I didn't know what was wrong. I mean I knew there was a problem but I didn't know what it was called. If you don't know about something, you can't really know you are doing your best to help it. It made me worry a lot about his future...and it was so tiring and frustrating having to constantly battle to get my voice heard" (Participant 2).*



*"I felt responsible. I blamed myself. I thought I had done something to cause this...lots of guilt and feeling really down. If they had helped me sooner, maybe I wouldn't have been so hard on myself all that time" (Participant 6).*

In situations where parents did not know what was wrong and were struggling to obtain a diagnosis, difficulties in the marital relationship could result.

*"The strain of not knowing what is going on...it had a strain on us. I didn't feel supported by my husband in trying to get a diagnosis. It affected the communication between us. That made me feel even worse" (Participant 1).*

Parents described being able to withstand the emotional strain of the battle by retaining feelings of hope that if they received a diagnosis, they might be able to do something for their child.

*"It was a tiring, frustrating time but I think we hoped that if they managed to find out what it is, then we would be able to do something for our child. That was the only reason we kept on fighting for a diagnosis because we hoped it would help in the end" (Participant 4).*

#### **3.2.1.1.2 Sub-category 'Receiving the LD/ASD diagnosis'**

Parents described a range of emotions and thoughts when they eventually received a diagnosis. These have been organised into two themes: initial feelings and initial thoughts.

##### **3.2.1.1.2.1 Experiencing the rollercoaster of emotions**

All parents described a range of emotions such as frustration, guilt, hopelessness and low mood. One parent received a diagnosis of Down's syndrome for her son at his birth.

She explained that receiving this diagnosis unexpectedly so soon after the birth was very painful.

*"It hit me like a bolt. It wasn't like the doctor was telling me he had a cold or a rash or something like that and if I took this medicine it would all go away.. I never had any pre-natal testing so I didn't know my son was going to have Down's syndrome until he was born. It hit me so hard. I felt hopeless and was depressed for what seemed like ages. I thought this was something I had done to my son. I can't explain how bad the guilt felt in those first few days and months" (Participant 5).*

Two parents spoke about their dissatisfaction and frustration with the outcome of the initial assessment in terms of feeling like the diagnosis given was vague and unhelpful. This led to continued feelings of blame and helplessness. Uncertainty in diagnosis spurred these parents on to continue the battle to receiving a more appropriate diagnosis by searching for information and requesting further assessment.

*"Once they finally got round to giving the diagnosis it was a big disappointment. They just kept telling me he had global developmental delay. They just said he was slow. It was so frustrating because I knew there was more than that. That label didn't tell me how to help him and it wasn't going to get me help. I didn't settle for that...after a while I asked again for another assessment" (Participant 2).*

*"They just kept saying at the start that he has additional needs. I thought that doesn't mean anything. I just felt like I didn't know what to do at first, I felt like I was letting down my son...it was really frustrating. I couldn't accept it really. I looked up the internet for stuff on autism and it was so obvious to me my son had it. I went back and tried to discuss my concerns again" (Participant 6).*

Other parents described feeling relieved once they had finally received a diagnosis. It confirmed their suspicions and provided them with a much needed explanation for their child's slow development and behaviour difficulties. Parents who described feeling relieved said that having a label allowed them to resolve feelings of guilt and blame as well as feel hopeful for the future.

*"I felt a big mission was complete once we had the diagnosis...I was upset for a lot of reasons but I was also really relieved I had a name for his difficulties...it wasn't that it was just behaviour problems that I couldn't manage, he had something genuine to account for the difficulties he was having. It meant I could be a bit more sure about what to expect and that I could do something about it" (Participant 1).*

*"It was a relief to know he had autism. It wasn't something we knew about before... so getting that diagnosis...yeah it did help of course. If there is a label, you can have a new start. It also feels like a relief because you knew that the battle to get the diagnosis was worth it" (Participant 4).*

One parent spoke about her varied emotions in response to the diagnosis of autism which she received after requesting further assessment after an initial diagnosis of global developmental delay. Her account portrayed feelings of both relief and distress.

*"We fought for so long to get a diagnosis. When we finally got it...I mean I won't lie, I was devastated. I cried all the way home. Although I was really upset, at the same time I knew we needed that diagnosis and it was a relief to get it. I knew he had this thing now and it wasn't something I did to him. I had those doubts for a long time and when we got the diagnosis, although I felt really bad it also made me feel better. You can start putting things together. It was a rollercoaster of emotions!" (Participant 6).*

### 3.2.1.1.2.2 **Loss of an anticipated future**

Parents gave insight into the various thoughts that they felt underpinned some of the initial feelings they experienced post-diagnosis. Many spoke about themes of loss and a lack of control. In addition, parents began to realise that their future dreams and expectations of their child's life and their own life as parents would have to change. This was found to be the case even in parents who had lived with the difficulties and suspected the diagnosis for some time before it was confirmed.

*"One of the first things I thought was that this is like a death. You haven't got what you thought you were going to get. You don't know what to do or how to fix things"* (Participant 5 talking about her thoughts at the time of the diagnosis of Down's syndrome).

*"I had looked forward to my life with my child and my husband so much. While I was pregnant I was so happy...I had loads of images in my mind of what it would be like to be a mother, to have a family...I was lucky to have a really great childhood and I wanted the same and more for my own child...I found it hard to accept that he wouldn't be able to experience the same things in the same way"* (Participant 1).

*"I had to give up all those images I had in my mind, images that I had built up over lots of years...of my child being academically clever, getting married, having children. We needed to give up the images of us being the parents we thought we would be and we realised we would have to be different parents now"* (Participant 7).

For some parents, initial thoughts concerned the life-long aspect of the diagnoses being difficult to accept as well as the uncertainty of developmental trajectories. This caused worry about the future for some parents who believed that change was possible, but who were also aware of the limitations imposed by the disability.

*"Even though my son wasn't a baby when he was diagnosed and we were already living with his difficulties, just knowing for certain the diagnosis is there now... knowing that it can't be cured, knowing that it is life-long...that was hard"* (Participant 6).

*"It was like, yeah we have this diagnosis but we didn't know what the future would be like. We accepted that he would probably make some progress but who knows if at some point he will stop making progress, he might reach his full capacity and then stop progressing. Not knowing these things is difficult"* (Participant 4).

Another parent remarked that while she felt upset at the diagnosis of autism in her child, the fact that she had already received a diagnosis of Down's syndrome nine years previously made the experience of the autism diagnosis slightly easier to cope with, whereby she didn't experience the same intensity of distressful thoughts and feelings the second time around. Furthermore, the very fact that she had already lived with the difficulties associated with his autism for a number of years helped her to cope.

*"It was different from the Down's diagnosis. That was an intense time for me. With the second diagnosis...I think if I hadn't already had a son with disabilities it would have hit me harder...I mean it was hard to know that this was it, everything was confirmed...but my son didn't change as soon as I got the diagnosis of autism. He was a bit older when he got the diagnosis so I had already been living with it...it was just now that it had a label"* (Participant 5).

In summing up experiences of receiving diagnoses in terms of initial feelings and initial thoughts, some parents explained that while their initial thoughts and feelings felt most intense at the time of the diagnosis and in the weeks (and in some cases months) after, they continued to intermittently experience the same feelings and thoughts at different points as their child was growing up.

*"The feelings don't suddenly go away after a few weeks. I wish they did because when I re-experience them, it's an upsetting time. There have been times when those feelings have come flooding back...like when my child started to go to special school or when I've seen him not manage with things that he should have been able to manage at certain ages...they feel less extreme as time goes on but I can't say they have disappeared" (Participant 1).*

### **3.2.1.1.3 Sub-category 'Evaluating the diagnostic process'**

In thinking about the diagnostic process as a whole, two main themes arose in parents' evaluation of it: communication with clinicians and parents as partners.

#### **3.2.1.1.3.1 Difficulties in communication with clinicians**

Parents noted a difference between themselves and clinicians in the way they communicated about and perceived their child. One parent explained that she felt her son had been 'depersonalised' by the use of medical jargon.

*"I know there were lots of problems they had to sort out...there was the physical stuff...the mental learning stuff...we saw so many different people. It was hard to make sense of things cos like...they all explained him in their own way. Some of them talked about him in terms of what symptoms he had...like a puzzle they needed to solve...me and my husband didn't see things like that...he wasn't a checklist of symptoms we were trying to tick off. He was just our little boy and I wanted them to see him as a little boy too...not just an interesting medical problem" (Participant 4).*

Other parents noted their difficulty in comprehending clinical terminology and related these problems in comprehension to feelings of worry about being able to manage their child.

*"I was really confused by all the different terms and explanations. I wanted them to speak simply in a way I could make sense of things. Some of them are good like that but the one who spoke to me was really confusing. It made me feel worried that I wouldn't know how to deal with things, that I wouldn't understand my son well enough"* (Participant 3).

*"I just sat there quietly trying to understand everything they were telling me. There were lots of words I didn't understand, words that doctors use...I wished they just spoke normally so that I could get what they were telling me"* (Participant 7).

Two of the first generation parents spoke about difficulties in communication with clinicians as being specifically related to their lack of confidence in using the English language. These parents felt that their understanding of the diagnosis, its implications and advised next steps were hampered by language issues.

*"It would have helped to have information in Urdu to take away with us. They had an interpreter but he wasn't medically trained and so we didn't fully understand what even he was telling us"* (Participant 3).

*"Because I don't feel confident speaking English, I was nervous in those meetings with the doctors. They should explain everything in right language...what difficulties my son has...what is learning disability. I didn't understand everything. I went away not knowing what I should do next. They shouldn't automatically think we have taken all the information in. I was scared to speak out, I didn't want to seem like I didn't understand"* (Participant 6).

The importance of information was clearly apparent in parents' responses to questions during the interviews, as was the varying perceptions of satisfaction with the information received.

*"The doctor who told us the diagnosis was really helpful. She asked us what we knew about autism. We told her we didn't know anything really. She spent quite a lot of time talking to us about it. The most helpful thing was being given information about how it would affect my child's life, she gave good specific information. She told us how to get support, DLA and things like that. It made us feel a bit more confident about what to do next" (Participant 1).*

Other parents felt that they were given sporadic and inadequate information about their child's diagnosis. This was related to feelings of frustration and helplessness about the future.

*"They just told me bits and pieces of information about the diagnosis. I think they thought I wasn't capable of hearing the difficult news but I wanted to know clearly what his difficulties were and how I could help...it was really frustrating" (Participant 2).*

*"If they don't give you good enough explanations and tell you in a straightforward way, it doesn't help you to feel better. It just leaves you feeling like you can't do good by your child if you don't know fully what the diagnosis means for the future" (Participant 5).*

Some parents discussed their dissatisfaction in relation to the way in which they were told about the diagnosis in terms of the setting and the time allocated to discussing the details.

*"I got a letter through the door telling me my son had global developmental delay. That was it. No meeting or anything. It wasn't till a lot later that I got to talk to the doctor about it in more detail" (Participant 2).*



*"It was really bad. The doctor came to my bedside and told me my son had Down's syndrome. He spent about two minutes with me and then he carried on with his ward round. I was just left alone" (Participant 5).*

As well as the information received, some parents also spoke about valuing clinicians whose interactions with them felt supportive and who were able to understand the emotional impact of the information being given.

*"They should recognise that it is a difficult thing they are telling us. They should ask how we feel about it all...not just give us the facts and tell us to go ahead deal with it" (Participant 4).*

*"The doctor was really helpful. She told me the diagnosis, a little bit about what it was but then spent time talking to me about my feelings about it all. I was shocked she did that. I was really touched" (Participant 1).*

### **3.2.1.1.3.2 Parents as partners**

Parents discussed that they expected and valued being partners with clinicians throughout the process of assessment and diagnosis. They wanted to be acknowledged as the experts on their own child.

*"I think it was good that they always asked me what I thought, my opinions. They asked me lots of questions. I felt like I had something to contribute to the whole process. Some other parents I know feel like with some doctors you feel a bit taken over...but I think its really important for them to remember that they might have the knowledge about the condition but we are the ones who know this child more than anyone else" (Participant 7).*

When parents didn't perceive clinicians to be treating them as partners in the diagnostic process, feelings of disempowerment and frustration often resulted. One parent related this to feeling discriminated against because of her background.

*"I think sometimes they just look at you and think you aren't as involved in your child's life as some White parents...so they don't involve you as much. I think they see people of my culture as being dismissive of things like disability and that we don't accept our children...I don't agree with that, it makes you feel so small and that your knowledge about your child counts for nothing" (Participant 3).*

#### **3.2.1.1.4 Summary and discussion of core category 'Obtaining a diagnosis'**

Consistent with a number of studies (e.g. Midence & O'Neill, 1999), parents in the present study were aware of problems with their child's development at an early stage. The feeling that something wasn't right led them to search for explanations. While some parents felt supported by health and education professionals in their search for a diagnosis, the majority of parents described it in terms of a "battle" to get their voices heard. Certain parents also felt discriminated against, with some believing that their battle for a diagnosis was made more difficult due to their ethnic background. Other parents felt that a lack of proficiency with the English further complicated matters. The emotional impact of this battle as well as the need to tolerate lengthy delays before finally receiving a diagnosis was clear from parents' narratives. Various other studies have also attested to the often slow diagnostic process and its relation to parental distress and dissatisfaction with services (e.g. Graungaard & Skov, 2006).

Once a diagnosis was eventually received, parents described a range of initial feelings from relief and hope to guilt, hopelessness, low mood and frustration. Themes of loss

were also discussed. Similar initial feelings have been widely reported in the child disability literature (e.g. Granggaard & Skov, 2006; Green, 2002).

There appeared to be differences between parents in their reactions to diagnoses in cases where they were clear-cut (e.g. autism) and cases in which there was diagnostic uncertainty (e.g. global developmental delay). While definite diagnoses appeared to be associated with feelings of relief and resolution of self-blame in some parents, diagnostic uncertainty led to continuing feelings of blame and guilt for other parents. These parents often felt the need to re-commence the “battle” for a more appropriate diagnosis. Hall and Hill (1996) have discussed that diagnoses such as ‘global developmental delay’ are often the result of a child’s difficulties not fitting into more precise categories but argue that it is no more than a circular definition and does not help parents’ understanding of their child. As found in other studies (e.g. Siegel, 1997), difficulties in the marital relationship during the diagnostic process were not uncommon.

In evaluating the diagnostic process, parents valued being treated as partners in the diagnostic process and appreciated clinicians’ respect of their position as experts on their own child. They also valued clear and adequate communication with clinicians who were sympathetic to their situation and who were able to recognise the emotional impact of the diagnostic process. Similar to previous studies (e.g. Graungaard & Skov, 2006), the present study found that some parents noted a difference in the way they perceived and communicated about their child compared to clinicians. Certain parents also spoke about their difficulty comprehending medical terminology which seemed to cause unnecessary anxiety. The need for adequate information about their child’s diagnosis was also emphasised by parents. A lack of information often left parents feeling confused, frustrated and worried about their ability to manage child. Additional problems in terms of language barriers to receiving appropriate information were also highlighted. In some cases, this appeared to be compounded by the assumptions made by health professionals about parents’ ability to assimilate and retain information given

at the time of disclosure. Indeed, the need for appropriate information has not been underestimated in the literature, with some researchers highlighting that parents commonly receive a lack of information and sufficient explanation about their child's diagnosis (e.g. Katbamna *et al.* 1998).

The findings in this section are broadly comparable to those found in research with White parents who have sought out and obtained a diagnosis for their child. It seems that regardless of ethnicity, parents appear to experience long delays between their first concerns and receiving a diagnosis, as well as having variable experiences in relation to receiving information and advice post-disclosure. The range of initial feelings and thoughts have also been found in studies carried out with White parents (e.g. Green, 2002). Important additional factors in the present sample and which have been found in other research with UK South Asian families (e.g. Hatton *et al.* 2003) are that some parents felt experiences of racism and discrimination by services impacted on the process of obtaining a diagnosis. For some parents, language and communication difficulties also impacted on their ability to battle for a diagnosis and understand the information given. This was found to be related to a sense of helplessness in exerting control over their situation.

### **3.2.1.2 Constructing meanings**

Subsequent to receiving a diagnosis, most parents spoke about the process they went through in coming to a stage where they could begin to make sense of the diagnosis. This core category of 'Constructing meanings' was subsumed into two sub-categories. These are outlined in Appendix 9.

#### **3.2.1.2.1 Sub-category 'Understanding my child'**

Following the disclosure of diagnosis, most parents discussed their experiences of coming to an understanding of their child and of the diagnosis. This sub-category is

comprised of five themes: the importance of acceptance; letting go of 'dreamed of child'; focusing on child's limitations; religious beliefs; and searching for positives.

#### **3.2.1.2.1.1    *The importance of acceptance***

For most parents, the period immediately after the disclosure of diagnosis appeared to be characterised by a number of searching questions about the meaning of the diagnosis, in terms of why it occurred, what it meant for their child, themselves and their future. Parents strongly asserted that while answering such questions was not a quick or easy process to undergo, beginning to answer them allowed them to move beyond the disclosure and to begin to arrive at feelings of acceptance of the diagnosis. Some parents expressed that while they experienced initial feelings of relief, this did not necessarily equate to immediate feelings of acceptance. There was a strong suggestion that acceptance required being able to arrive at an understanding of their situation.

*"Acceptance is really hard. It isn't an overnight process. It starts from when you are given the diagnosis...even though I thought it was a relief to get the diagnosis, it didn't mean it was something I automatically accepted" (Participant 1).*

*"I suppose I needed to start making sense of the things as soon as we got told about the autism. Till then, there was always the possibility that they could turn round and say it was just behavioural problems that they could help me to get rid of. When that didn't happen, I knew I needed to accept that and get my head around this situation" (Participant 6).*

*"We spent a lot of time trying to understand what we had to do as parents, why this happened to us, our child...we had a lot of questions in our head for quite a while after we heard the diagnosis...no easy answers to those questions...but we knew that we had to find a way to move past the diagnosis and the sad and worry...but we knew before*

*that could happen we needed to understand the diagnosis and what it meant for us"*  
(Participant 4).

### **3.2.1.2.1.2 Letting go of 'dreamed of child'**

Some parents explained that a part of accepting the diagnosis included the necessity of dealing with the loss of their imagined child. Although some parents reported this as being amongst their initial thoughts at the time of the disclosure, they spoke more about the process of eventually learning to let go of these images in the weeks (and sometimes months after) after the initial diagnosis. Most of the parents experienced this differently, with some expressing that they let go of these images relatively quickly and easily by realising the futility of holding onto them. Other parents still held on to these images. Having uncertainty in diagnoses appeared to make it harder for parents to let go of these images, since they tended to oscillate between periods of hope and uncertainty as their child underwent further assessment. Parents who were able to let go of their 'dreamed of child' wanted to know what the future might bring. For some parents, creating images to replace the old images involved seeking out information which allowed some to create realistic and positive views of the future. Other parents preferred to limit their views about the future since it resulted in feelings of anxiety about an uncertain future. Coping with uncertainty about the future led some parents to 'live one day at a time'.

*"I let go of those dreams for my child but it left me feeling a bit empty cos I didn't really know what life would be like now. I needed to know though...I needed a vision of what our lives would be like. I looked out information on the net about learning disabilities, watched documentaries and stuff...I think that helped a bit"* (Participant 1).

*"I found it hard to deal with not knowing what the future would bring. Sometimes when I think about it, I just get so worried about my son. I worry...like what will*

*happen when I'm not here anymore, how we will cope...I block those feelings out usually...its better for me to just take it one day at a time" (Participant 4).*

*"Things weren't clear when I first raised my concerns so they carried out more assessment...I clung onto the hope that they would tell me things were better and we could be a normal family, like I always took for granted we would be" (Participant 3).*

*"We got to the point where we still weren't 100% happy with our situation but we realised that there was no point sitting around being depressed about what could have been...that just holds you back. Yes, we still have worries but we try and do best by our children and to do that you need to look at them differently, not like the child you thought you would have" (Participant 7).*

### **3.2.1.2.1.3 Finding meaning in religion**

All of the parents made reference to various religious or spiritual beliefs that they held which they drew on at various points in the aim of reaching an understanding of their child. Reference was made to God in the understanding and explanation of disability with variation in the reasons given for God having caused the child to have a learning disability and/or an ASD. Some parents believed their child was a gift or a blessing from Allah (God), while others saw it as a test of their abilities as a parent, with the promise of future reward.

*"Allah can see how we cope with him...He will be looking to see if we are caring enough for him. There is success in this if we do best by him" (Participant 2).*

*"Thinking that Allah gave me this boy because we are able to look after him changed our lives. I needed to think in this positive way. Allah looked to me, he saw something in me to make Him think I can cope. It means I am a special person, I'm not to blame. It gives me strength believing this" (Participant 5).*

One parent explained that for some time after the diagnosis, she believed that the diagnosis was a punishment from God for things she felt she had done wrong in life. However, she explained that with increasing knowledge about the diagnosis and explanations from health professionals, she came to an understanding that she wasn't to blame.

*"At the beginning and for a while after, I used to blame myself. I thought this is something Allah is punishing me for. That made me feel bad within myself. With time, I started to think less like that and I think the way doctors explained things was helpful to let me see I wasn't to blame" (Participant 6).*

#### **3.2.1.2.1.4 Focussing on child's limitations**

In coming to an understanding of their child, all parents explained that there were periods where they found it difficult to look beyond their child's limitations. For most parents, this occurred when their child did not fulfil normative expectations and/or when they realised they would be unable to fulfil traditional cultural expectations in the future. Comparing their child to other typically developing children appeared to make these feelings more acute. However, some parents acknowledged that while their expectations weren't fulfilled, reminding themselves of their child's needs allowed them to alter their expectations and continue to move on. Other parents had appeared to reach a stage where they realised that comparing their child to typically developing children was unhelpful and limited their capacity to adjust positively. Lastly, for certain parents, difficulty in tolerating their child's limitations led them to search for a cure for their difficulties.

*"I know I shouldn't do it, but sometimes I catch myself comparing (son's name) to other children. When they are the same age and when they are so different ability-wise, that is hard...the acceptance comes and goes then...the things he struggles with become so much more obvious" (Participant 2).*



*"I pray a lot...like I pray that my son will get a cure one day. Maybe it won't happen but as long as I keep praying, maybe they will find something that cures the autism"* (Participant 6).

*"Being a Muslim Pakistani dad makes it very important for me to ensure my children get married. It's part of Islam, a parents' obligation. Knowing that my son probably won't be able to get married is very hard to accept. That will reflect on me"* (Participant 7).

*"It's true that if you don't change the way you think, if you always think you wanted to have a normal child, if you always compare your kid to normal children, then you will never really move on. You will be stuck"* (Participant 5).

#### **3.2.1.2.1.5 Searching for positives**

While a focus on limitations was apparent in parents' accounts, also apparent were positive constructions held in relation to the positive impact that some parents felt their child had on their family. There was the recognition of the need to think positively to further the process of adjusting to the diagnosis. Indeed, some parents reflected on being able to gain a sense of control and of being a competent parent by thinking about their child differently. In forming positive constructions, some parents appeared to confront their own beliefs about disability and, in the process of doing so, were able to let go of previously held misconceptions, normalise disability and re-conceptualise the meaning of achievement and success. However, not all parents reported reaching the stage of being able to form positive constructions. It appeared to be the case that parents who had lived with the diagnosis for a greater number of years were able to do so more readily. Even in those parents reporting positive constructions, they expressed that this did not mean they no longer experienced negative thoughts, but rather that they were better able to balance out such thoughts with more positive perceptions. Furthermore,

there was a sense that positive perceptions may fall away during certain periods throughout the child's development e.g. starting school.

*"At the start I didn't think I could cope. I thought there was no way I could raise an autistic child...but with experience I started to latch onto the progress my son was making...that boosted my confidence and helped me to stop dwelling on why this happened to me. Our family is closer now since the diagnosis. When our children aren't there, we feel a big hole" (Participant 1).*

*"My child might not become the next Einstein, but he is still a human being! You get to the point where you realise that a disability doesn't make someone less of a person. It could have happened to anybody...and anyway no-one is perfect, even in people who don't have disabilities, we all have things that make us different. I am so lucky to have my child...I get so much enjoyment from him...there are some much worse off than us" (Participant 5).*

*"I saw that my child was progressing. Even if it was slow progress you have to hold on to that. I've definitely changed my idea about what an accomplishment is. I notice the little achievements now. My son at age 9 asked me for a sandwich for the first time and it was such a happy day for me, I was so proud" (Participant 6).*

*"Even though there are highs with our son, sometimes its hard to hold on to them...its like you need to start your thinking process all over again about him when something happens...like when he started special school...it hit me then the extent of his difficulties...you go through all the negative emotions again, I needed to try understand my son again in this new situation. I think there will always be highs and lows like that though, I think I am prepared for it!"(Participant 7).*

### 3.2.1.2.2 Sub-category 'The influence of others' meanings'

While the previous sub-categories outlined the processes parents appeared to go through in understanding their child, it was clear that meanings were not constructed exclusively at the individual level. Most parents had to contend with the meanings brought to the diagnosis by others. This sub-category has been divided into the following themes to reflect these other influences: family and friends, wider society, and service professionals.

#### 3.2.1.2.2.1 *Family and friends*

Some mothers spoke about the necessity for themselves and their partners to hold a shared understanding and acceptance of their child. This appeared to allow both parents to more readily accept the diagnosis compared to parents where such a shared perspective was not held. Two mothers explained that following the disclosure of the diagnosis, they spilt with their husbands due to a lack of shared acceptance. Cultural influences tended to be important here.

*"First born males are really important in our culture. I think for my husband that was difficult because he tried to save face by pretending nothing was wrong...but I knew there was...we just weren't on the same page" (Participant 1).*

*"There was a pressure on my husband from his parents to remarry because he was young, able and his family told him he would be able to find someone else. They felt like their son would become tainted and less respected in our community if he stayed with me. We ended up splitting up because he continued to blame me for what happened to our son and I couldn't take it anymore" (Participant 2)*

*"When we got the diagnosis, my husband was sad but he said he was going to make a decision to live with it...the way he dealt with it helped me...he was strong for me" (Participant 5).*

Some parents also discussed feeling frustrated at their family's lack of understanding of their child. For example, some family members tended to medicalise the disability and parents felt this was due to medical illnesses being easier to accept than learning disabilities or autism. Dealing with their understandings often felt stressful for parents, particularly when diagnoses were first given. They expressed that it would be helpful for clinicians to offer a session to important family members in order to, amongst other things, remove cultural myths associated with disability. Other parents expressed a feeling of frustration that family members treated their child differently, while other mothers were blamed for 'inflicting' the disability on to the child. Some parents also spoke about assumptions made by friends and relatives about parents' ability to participate in social activities and became aware that they were excluded from social events.

*"My mum and dad love him but they keep saying he will grow out of it...but I don't find that helpful. I wished they could understand him better. Having a session after the diagnosis with family would be helpful just so they can hear first-hand from doctors what the situation is" (Participant 6).*

*"Family and friends can be really negative...some don't take my son out when they take all the other kids out. They think just keep him inside, put him to bed...like it's a cold or something he has" (Participant 3).*

*"I don't always feel welcome at family events. I know some just think I should stay at home with my son...I've stopped being invited to some things...one cousin even said to my face not to have any more children because I obviously inflicted this disability on my son"(Participant 5).*

Some mothers explained that their own mothers had expressed a wish for their child's diagnosis not to be disclosed to others in their community. This related to the fear of

gossip and a fear that suitable candidates would not be found for marriage in the future. One mother felt that this led to feelings of restriction and ongoing difficulties in adjusting to her situation, while another made a conscious decision to share the diagnosis with others, despite her mothers' wishes, as a way to increase others' awareness of autism.

*"My mum told me not to tell anyone about his learning disability. She thinks my son will never be able to get married if people find out he has this. It holds me back. If I could share this openly with other people it would be much easier for me to accept things, live with it" (Participant 2).*

*"At the start I tried to respect my mum's wishes not to tell anyone but as my child got older and as I accepted things, I didn't see no reason for me to hide my son away. I have started to tell people about it...if you don't share these things, people are never gonna learn about disability and they will always think it's a bad thing...I want them to see its not" (Participant 1).*

### **3.2.1.2.2.2 The wider Pakistani community**

All parents discussed that in the process of constructing their own meanings about the diagnosis, they were also required to deal with the meanings that other people in wider society brought to their situation. More specifically, most spoke about the constructions of disability held in individuals of the same ethnic and cultural background as themselves. Where such constructions had a negative focus, parents generally felt that this was due to a lack of education about disability and felt that this was more pronounced in first generation individuals. All of the accounts reflected the challenge in dealing with negative social judgments before and after the diagnosis. Parents described how they felt people judged their child's behaviour unfairly and some felt this reflected directly on them. Some parents reflected on the fact that dealing with stigma after a diagnosis was given was easier due to their own construction of the diagnostic label as

something which could be used as a response to, and hence a defence against, social judgments. In this way, there was evidence that some parents underwent a change in their attitude towards negative social judgments over the years. However, other parents were less happy to use the label in such a way, which often resulted in self-imposed restriction and ongoing difficulties in adjusting to the diagnosis.

*"In Pakistani culture, some make it hard for you to accept, especially the older ones... You are either seen as able or not able...with no in-between. They see the disability before the child and it really got to me in the early stages but I think I am getting to the point where I care less...it still hurts but I try not let it affect me as much. Understanding your child for yourself makes you stronger about these things"* (Participant 4).

*"People from our culture especially, they don't understand autism. I used to notice being given dirty looks if (son's name) was acting up in the street. I used to feel ashamed and I started to avoid places because I worried about what our people would think. I do better now, I don't let it get to me as much...but sometimes if I haven't had to deal with it for a while and someone says something really ignorant it can set me back a bit"* (Participant 1).

*"Pakistani people would say to me you had your son when you were over 30 that is why he has problems. One other person even said it was because someone put black magic on me. Even though I knew that wasn't true, it made me really upset. With time, I started to use the label as a way to explain that it wasn't my fault or due to some other silly explanation"* (Participant 5).

*"In our culture, I think if someone has a disability they don't want to know you or include you in things. They don't know about these things so prefer to stay away from it...some view people with learning disabilities or autism as if they are nuts. I avoid*

*weddings and parties now cos people just make you feel invisible...because I am divorced too, people make you feel even more invisible" (Participant 2)*

### **3.2.1.2.2.3 Service professionals**

Parents' accounts also suggested that the process of constructing meanings was also influenced by the meanings provided about disability by the various service professionals they came into contact with over the years. Some parents felt that professionals were too symptom-focused and areas of limitation were often emphasised at the expense of their child's strengths. However, other parents who found it difficult to accept the diagnosis discussed that contact with professionals post-disclosure was often helpful. They explained that professionals often spoke positively about their children and, in doing so, helped them to gain another perspective on their situation.

*"I've often felt that some of them just look at what my son can't do...big long lists of things...that can feel depressing...its no wonder its hard to accept things if you are constantly just told what you son can't do. Some look at the positives too but not enough of them do. It would help us as parents to hear what our children are good at too" (Participant 3).*

*"With the diagnosis of Down's syndrome that was harder than the autism, I just couldn't see at the time how my son would have a good life, a good future but some of the doctors in those early years, they were really good...they pointed out to me all the things he was doing well, helped me to see it wasn't a bleak future...that didn't happen quickly but they helped me to think differently" (Participant 5).*

### **3.2.1.2.3 Summary and discussion of core category 'Constructing meanings'**

Once a diagnosis was received, all parents discussed the need to make sense of it. Indeed, the importance of discerning meanings in the adjustment process following a

stressful event in order to maintain a resilient outlook has been widely reported in the stress and coping literature (e.g. Grant *et al.* 2007; Meichenbaum & Fitzpatrick, 1993; Taylor, 1983). Parents' accounts suggested that in order to construct meanings, they had to arrive at an understanding of their child. All of the parents felt that in order to do this, they needed to accept the diagnosis as an integral part of the child and the family. For some parents, coming to this realisation included lots of existential questions about the meaning of the diagnosis.

In the process of constructing meanings, parents spoke about letting go of previously held images of their 'dreamed of child'. Certainty of diagnosis seemed to be important, whereby a more definite diagnosis appeared to provide a concrete need for parents to let go of these images, whereas parents who had diagnostic uncertainty held on to these images while further assessment was carried out. Once images were let go, parents were faced with the difficulty of coping with an uncertain future. Parents dealt with this in different ways. Some sought to create new images for the future by seeking out information about the diagnosis, allowing them to make plans for the future.

Seeking out information is often considered to be a problem-focused coping strategy allowing parents to regain some predictability and control after a stressful event (Taanila *et al.* 1998). Parents appeared more able to construct realistic future images by using problem-focused coping strategies than parents who appeared to have an ongoing struggle with the emotional impact of the diagnosis. Indeed, there was the suggestion by some parents that analysing too much (or emotion focused-coping) was a negative thing in itself, whereby it held parents back in their acceptance and adjustment if it carried on for too prolonged a period after the initial disclosure.

While some parents sought out information to cope with an uncertain future, other parents preferred to 'live one day at a time' and limit their view of it. To do otherwise, may risk overwhelming anxiety or disappointment. Some researchers have suggested



that living one day at a time can leave parents feeling out of control and wary of making decisions about the future (e.g. Grant, 1990), while others argue that it serves as a way of coping by increasing manageability in the short-term (e.g. Graungaard & Skov, 2006).

In the process of letting go of previously held images and in an ongoing attempt to understand their child, parents reported a tendency to focus on their child's limitations. This appeared to be pronounced when there was a mismatch between parental expectations (including cultural expectations) of their child and the reality of their child's abilities. Focusing on limitations also appeared pronounced when parents compared their child to typically developing children. This led to some parents continually having to construct new meanings or revisit old meanings. This supports the argument that the process of parents of coming to an understanding of their child following a diagnosis is an ongoing process throughout the child's life, triggered by situational circumstances (e.g. Wilgosh & Scorgie, 2006). Some parents who appeared unable to tolerate their child's disability and the associated limitations reported that they prayed for a cure. Indeed, the search for a cure has also been proposed as part of the adjustment process for White families (Nickel, 1996), but there is a concern that while this may help parents to cope, a belief that their child's disability can be completely overcome may leave parents particularly vulnerable to claims for a cure.

While there was a focus on limitations in the process of understanding their child, other parents spoke about the positive characteristics of their children and the positive impact they had on their family. Some parents also cited worse case scenarios, re-evaluated the position about the identity of the child with the disability as a human being as well as re-conceptualising the definition of achievement. As in other studies, there was evidence of a diagnosis bringing families closer together (e.g. Midence & O'Neill). Religious and spiritual beliefs also appeared to help some parents to positively re-frame their situation and understand disability. Indeed, Zuniga (1998) argues that religious attributions may provide a psychological mechanism for a parent to manage their feelings about caring

for their child. However, it was also clear from parents' accounts that while many held positive perceptions, negative or stressful experiences continued to occur alongside them, a finding reflected elsewhere in the literature (e.g. Stainton & Besser, 1998).

These positive impacts appeared to reinforce the meaningfulness of parenting a child with a disability, perhaps relating to establishing a sense of coherence as outlined in the literature (Olsson & Hwang, 2002). In addition, the findings relate to wider research on adjustment following a stressful event which suggests that being able to shift the way in which a situation is assessed and cognitively processed can lead to it being interpreted in a more positive way and, thus, rendering it more acceptable and manageable (e.g. Grant & Whittell, 2000).

The extent to which positive impact or positive characteristics of the child were noted in the current study may have been related to a number of factors. For example, for parents who were able to maintain a positive view, it may be that they possessed traits before having their child i.e. optimism, perceived competence or resilience. A greater number of years since diagnosis and certainty of diagnosis also appeared to make a difference in positive perceptions. Indeed, Poehlmann *et al.* (2005) have suggested that the longer parents have lived with a diagnosis, the more time they have had to reflect on their child's positive attributes and to develop more positive perceptions.

The process of constructing meanings was also influenced by the meanings that others' brought to the situation i.e. family and friends, wider society and service professionals. These meanings reflected social, cultural and medical constructions of disability. When negative constructions were imposed on parents, this appeared to affect their own meanings and ability to adjust, particularly in the early stages following a diagnosis. For some parents, stigmatising and discriminatory views from both within and outwith the family often led to feelings of exclusion and restriction. Research with White families has found similar responses to negative social judgments (e.g. Gray, 1994). It is clear that the

parents in this study were subject not only to discriminatory views about disability generally, but also discriminatory views relating to being of a particular cultural group. However, with time and experience some parents reported feeling better able to deal with this.

Some parents noted that having a shared understanding and acceptance of their child's diagnosis with family members was extremely important. While some mothers reported that having no such shared understanding led to marital difficulties, other mothers reported that they were able to achieve this, perhaps reflecting the notion of possessing positively-focused family schemas (McCubbin *et al.* 1993) i.e. the shared beliefs and values that a family develops which can help maintain a more general positive view of events and, thereby, adjust to challenges.

### **3.2.1.3 Exploring possibilities for action**

Following receiving a diagnosis for their child and subsequently experiencing a range of initial feelings and thoughts as well as attempting to begin the process of constructing meanings, most parents spoke about how they sought to access appropriate supports for their child and themselves. This sub-category is subsumed into three sub-categories as outlined in Appendix 10.

#### **3.2.1.3.1 Sub-category 'Recognising the importance of exploring possibilities for action'**

All of the parents spoke about the need to explore possibilities for action following a diagnosis. Most explained that being able to accept the diagnosis and come to an understanding of their child opened the door to allow them to seek strategies. Parents' accounts seemed to suggest that the reason for doing this was to allow them to take some control of the future and to increase feelings of manageability. In addition, the

need to act was often described as a way of not giving up any feelings of hope for the future. The fear of some parents about possibly realising in the future that they had failed to get the right supports in place seemed to add to their need to act. In addition, the importance of finding possibilities for action seemed to vary across the child's life, whereby parents were most often involved in seeking supports soon after the diagnosis. Once supports were in place, the need to find possibilities for action decreased. However, parents' explanations suggested that once the child presented with new needs or if they became concerned about an aspect of their child's development or behaviour, the need to find possibilities for action resumed.

*"Once you get your head around things initially, you can start to think about what you need to do. I think doing that helps a lot of parents to feel hopeful...cos you are headed in a direction of helping your child for the future" (Participant 4).*

*"I kind of think if I didn't access supports then in the future I might ask myself why I didn't do this or do that for my son...I don't want to feel that guilt in the future knowing I haven't done the best for him" (Participant 2).*

*"After the diagnosis, there were lots of options we had to look through...schools, speech and language therapy, nursing...but then once all those things were in place things settled down...now and again we need to get more help...just depends on what is going on for our son at the time and if we have any worries" (Participant 1).*

### **3.2.1.3.2 Sub-category 'Formal supports'**

All of the parents spoke about their experiences of accessing formal supports i.e. health, education and social work. This sub-category is comprised of two themes: accessing formal supports and evaluating formal supports.

### **3.2.1.3.2.1 Accessing formal supports**

Parents felt a responsibility to access supports but some felt that the challenge of doing so was hinged on professionals' reactions to them. Therefore, some felt the need to present themselves as confident and intelligent so that their requests for supports were taken seriously. In doing so, some parents felt they became more assertive in their dealings with services. There was also a consensus that generally services weren't always proactive in suggesting areas of possible intervention and that parents had to be assertive in highlighting areas of concern. However, for parents who lacked familiarity with how services are set up and who did not feel confident in using the English language, this often meant that they did not always receive the services they would like. Where services were offered, two parents cited cultural and religious reasons for why they were reluctant to access these. A reluctance to use supports often led to increased feelings of caregiving burden in these mothers.

*"I think you do better when you present yourself in a certain way...when you are sure you know what you want and why...I think you get taken more seriously that way"*  
(Participant 1).

*"I didn't know what would be the best way of getting things in place...you have to know how services are set up and it's a lot to get your head around...even harder when your English isn't good"* (Participant 7).

*"They offered me respite but I said no...its very tiring but I look after him myself. Who knows what they give our children to eat, maybe not Halal food...and I also heard they don't separate up girl and boy bedrooms. I don't like these things"* (Participant 6).

### **3.2.1.3.2.2 Evaluating formal supports**

Parents who had accessed formal supports had a range of experiences over the years since receiving a diagnosis. Most felt that despite experiencing gaps between receiving a

diagnosis and supports being put in place, they were now gaining valuable practical support for their child. However, the main area of concern related to a feeling that there was a lack of post-diagnostic support specifically for parents; while most felt that their child's needs were generally well catered for, they felt professionals often overlooked parents' own need for emotional support. This need was magnified for some parents due to a feeling of being unable to share their thoughts and feelings about the diagnosis and its implications with members of their family, often due to their lack of understanding about the diagnosis.

*"Even though it can take a while to get things set up and you asking for things many times, I think services generally do okay after a diagnosis in terms of getting all the right things in place for the child...of course that's the most important thing, but I think sometimes the parents feelings and needs get missed out" (Participant 4).*

*"I worked hard to get the right things for my son...he got nursing input, speech and language therapy...I got him into a special school. The school people, the health people were good...they told me all the options open to us. It was really helpful, it made me feel like things were going right" (Participant 5).*

### **3.2.1.3.3 Sub-category 'Informal supports'**

In addition to talking about their experience of formal supports, parents also spoke about informal supports, in relation to two main themes: family/friends and parent support groups.

#### **3.2.1.3.3.1 Family and friends**

Only one mother spoke about benefiting positively from spousal support throughout her child's life so far, who it especially helpful in the early stages after the diagnosis, with support from wider family and friends becoming more important over time. Other

parents felt a lack of support from their partners, wider family and friends. This appeared to increase some parents' sense of isolation and difficulties adjusting to the diagnosis and its implications. Some of the parents who had experienced or continued to experience isolation because of a lack of informal support felt that services often assumed that because they were part of seemingly 'robust' family networks, they were coping well.

*"My husband was there for me right from the start. We made decisions together, we understood things the same way...I think we helped each other to adjust...family and friends didn't really understand the diagnosis at first but with time they have and that has helped too" (Participant 5).*

*"Just because we look like we are a close family, it doesn't mean everything is okay. They shouldn't assume that our extended families help us. I have the main responsibility for my son...the others in my family just leave me to it" (Participant 2).*

#### **3.2.1.3.3.2 Parent support groups**

All of the mothers explained that over time, they gradually began to seek out other sources of informal support; most were involved in a parent support group aimed at Black and Ethnic Minority parents with a child with disabilities. All of the mothers spoke positively about this group despite some experiencing an initial wariness about attending. Parents explained that such groups were an invaluable source of advice as well as providing comfort that there were other parents with similar circumstances. Indeed, the group appeared to be key in developing positive perceptions by being able to learn from others' experiences. In addition, most felt that they were an ideal forum to raise cultural and religious issues in relation to raising a child with a disability. One parent also discussed taking an active role in the organisation of various parent support groups in the years following the diagnosis of her children. Her account seemed to

suggest that she gained a sense of empowerment within the group by using her parenting experiences as a resource that could be made available to other families.

*"What was really helpful was meeting other families who had good attitudes towards disability. It is good to see a similar child who is older and who has progressed and how with time their parents have adjusted well and cope great. We came away feeling that our child could progress forward too and that we could manage just like them"* (Participant 6).

*"These other mums they are in the same boat...they need to deal with issues with wider family members too...they have all the same cultural expectations on them...we speak about those things and it helps to get some of those frustrations off our chests!"* (Participant 2).

*"As time went on, I started to take a more active role in the group...encouraging people to come, arranging speakers and stuff, sharing my experiences of getting services...I thought it was a good way to help other mothers and I enjoyed it too"* (Participant 1).

Both fathers reported that they attended no parent support groups. Both felt that they were primarily geared towards women and, therefore, felt reluctant to attend. Practical constraints such as work commitments also seemed to present barriers to accessing informal supports. However, one father commented that he would find it helpful to have dedicated groups for men to discuss their experiences of parenting a child with a disability.

*"My wife goes to those things, not me...mostly women go to these things but as time has gone on I have thought it would be good to have a chance to meet other fathers who are in a similar situation to me. I don't think anything like that exists though"* (Participant 7).



#### **3.2.1.3.4 Summary and discussion of core category 'Finding possibilities for action'**

Parents described their need to explore possibilities for action once a diagnosis was received. It was of paramount importance for parents to know within themselves that everything possible had been done for their child, inside and outwith formalised systems of care. Often this was as a way of increasing feelings of manageability and a sense of control over the future. This is in support of arguments that despite the difficulties associated with learning disabilities and ASDs, parents are generally not passive upon receiving a diagnosis and rather they aim to take an active role in the management of the disability (e.g. Nota *et al.* 2003). In terms of formal supports, parents felt that they needed to present themselves as assertive and intelligent in order to gain appropriate supports for their child. However, for parents who lacked familiarity with the healthcare system and who lacked confidence in using English, they reported struggling more in getting supports in place. Generally, it was felt that post-diagnostic support in relation to the emotional needs of parents was lacking, a finding also outlined by Hatton *et al.* (2003). This coupled with an inability of most parents to seek support from wider family members and friends may lead to difficulties with adjustment. There was also some suggestion that there was a reluctance to use formal supports due to concerns about that they were in some way religiously or culturally insensitive.

Over time, most parents began to attend parent support groups. As reported in other studies, parents gained hope from other parents' experiences (e.g. Kausar *et al.* 2003), as well as developing a sense of control by using the resources of others to generate their own possibilities for future action. Indeed, researchers have argued that the nature of social support that families receive may be crucial in considering their adjustment (e.g. Hastings *et al.* 2002).

#### **3.2.1.4 Reconstructing roles and identities**

In the process of obtaining and understanding a diagnosis, and beginning to adjust, most parents spoke about how they felt their roles and identities had changed. This core category of 'Reconstructing roles and identities' was subsumed into three sub-categories as outlined in Appendix 11.

##### **3.2.1.4.1 Sub-category 'Negotiating multiple roles and identities'**

All parents' accounts reflected the challenge of negotiating multiple roles and identities in the process of adjusting to the diagnosis and their child. This sub-category is comprised of two themes: the centrality of the caring role and balancing the needs of others.

###### **3.2.1.4.1.1 *The centrality of the caring role***

Some mothers spoke about changes they experienced in relation to their identity and roles once they had received a diagnosis for their child. Some focused on the care-giving role to the exclusion of other roles e.g. employment. In this way, there was a sense that some mothers gave up their identity as working women to concentrate on parenting and advocating for their child. For some mothers, this was a satisfactory role but for others it felt restrictive. Although only two fathers were interviewed, their accounts appeared to suggest that they took a different role than their partners. Both described that while they accepted responsibility for the parenting role, their roles differed from their partners, in that they were less involved in the day-to-day caring but more involved in the traditional breadwinner role. Some mothers identified with this in their own husbands and for some, it reinforced their sense of restriction in the caregiving role, while others recognised this as conforming to the perceived traditional role of the mother as the main carer.

*"My life just became about caring for my son. He had lots of needs and I was just focused on meeting those needs. I stopped my work for a few years because I wanted to be there for my son...it was very tiring though and I did start to miss being at work"* (Participant 5).

*"Sometimes I just felt like a carer to my child...not his parent. It's like my identity was now as a carer, an advocate... and that was it. Of course, I love my son and would do anything for him but sometimes I feel I've lost a bit of me in this role"* (Participant 4).

*"My wife and I we do different things for the family...me, I work and provide for them and my wife she stays at home and looks after the kids. I don't really get involved in that side too much, I am always pretty busy working. It is important for me to provide for his future"* (Participant 7).

#### **3.2.1.4.1.2    *Balancing the needs of others***

Mothers' accounts suggested a strong conflict in meeting their needs of the child with the learning disability and/or ASD and providing enough time to other children and to the marital relationship. Some mothers felt that their other children and their husbands had become secondary priorities, particularly in the early stages of adjustment. Some noted the tension that this could have in their families. The majority of mothers also spoke about their multiple roles as Pakistani Muslim women within their extended families. Some felt the impact of familial obligations as not only a wife, mother and carer, but also as a daughter-in-law to her husbands' family. For some mothers, feeling unable to fulfill familial obligations often led to scrutiny and hostility from some extended family members. Other mothers continued to struggle with balancing their multiple roles and meeting the needs of multiple others, even though it impacted on their emotional and physical wellbeing.

*“At the start, I mean I don’t think I was aware of it at the time but I pushed my other kids and my husband to the side, it was like I had 100% focus on (name of child with disability). My husband would make little comments about it but at the time I didn’t care” (Participant 6).*

*“It was like my wife became a bit selfish. I mean I understand why all her energy was focused on our son but it brought tension in our marriage because I felt like she wasn’t there for me anymore” (Participant 3).*

*“What was really hard...and still hard...is being able to manage the needs of my husbands family. They often ask me to help with things, its sort of my duty...you can’t really say no cos it looks really bad...it can be really exhausting trying to keep everyone happy” (Participant 4).*

*“I eventually had to let my husband’s family know that I couldn’t manage to do what they needed me to all the time and also look after my own family. It was hard telling them that cos...like with daughter-in-laws...there is an unspoken assumption that she will work her hardest to keep the family happy. When I said it to them, I didn’t get a good reaction...they accused me of being selfish and a bad wife...I know they judged me a lot.. It hurt me at the time but I am so glad I managed to stand up to them” (Participant 5).*

#### **3.2.1.4.2 Sub-category ‘Embracing a new identity and roles’**

Most parents’ accounts suggested that the further along they got in the adjustment process and with an accumulation of experience in parenting a child with a learning disability and/or an ASD, they came to form and embrace new roles and identities, as well as notice ways that they felt changed as a person. This sub-category consists of two themes: re-evaluating wider identity needs and a new me.

### **3.2.1.4.2.1 Re-evaluating wider identity needs**

Some parents noticed a change in their role in the early stages from 'trying to fix their child' to accepting the disability and, thus, feeling more content to undertake a role of focusing on making their child, their family and themselves happy. Experiencing success in this new role appeared to result in a sense of competence in parents. Also, parents who previously gave up their own needs spoke about coming to a stage where they could re-focus on their own needs and wishes. For some, this involved relinquishing some of their caring role to re-enter the workforce. For one mother it involved re-evaluating her identity as someone who was able to draw on her experience of parenting a child with a disability to improve 'the system', and fight for equality rights in relation to disability and ethnicity. For parents who embraced their wider identity needs, this appeared to give them a sense of purpose and achievement. However, there was also the sense that the process of evaluating identity needs and priorities for the self changed over time, occurring alongside changes within the child or family system

*"Over time, I have stopped trying to fix my child, pushing him to do better, achieve...now I focus on what he can do instead of what he can't and I just try concentrate on what makes him and my family happy...I feel like a better parent and wife because of it... but that feeling has only come with acceptance and time"*  
(Participant 6).

*"When my son turned seven, I decided it was time to go back to my job in the hospital part-time. I needed more of a balance...but it does sometimes get hard being at work though...like when there's been a period when he has been unwell or something...at those times I wonder what I am doing at work and usually take annual leave or something just to look after him at home"* (Participant 5).

*"I have learnt a lot from this process...from battling to get a diagnosis, to adjusting to the challenges that autism can bring...so I've involved myself with other Asian mothers and try help those who aren't as confident as me to fight the system too so they can get what they need. If I have the knowledge and experience to help these women, then I will. I like doing it" (Participant 1).*

#### **3.2.1.4.2.2 A change for the better**

While parents still continued to experience worry and stress about the future and day-to-day challenges in their parenting role, all of them evaluated how they felt parenting a child with a disability had changed them as people, by reflecting on how their child provided them with opportunities to learn and develop as an individual. For example, some parents noticed a change in their attitudes towards disability and felt they now possessed broader world views. Some parents also felt they had become more assertive and expressive by standing up for themselves. Other parents reported learning about what was important to them in life, being more able to appreciate 'the little things', and valuing the place of disability in their lives. One father explained that while he took time to accept the diagnoses of autism in his sons and subsequently time to accept responsibility for caring for them, reaching a point where he was able to do so had enriched his life, given him a heightened sense of purpose, and strengthened his marriage.

*"I feel like my son has changed me...for the good...before if I saw a disabled child, I probably wouldn't have taken any notice. Now I can see people for who they are, not what they are and I'll never think disability is just a bad thing with no good...for me, I think we are lucky to have this child and sometimes I think those families without a child with disabilities...they are the unlucky ones" (Participant 5).*

*"I have become a much stronger person since having my children...much more confident. I was such a timid person before trying to get a diagnosis but the whole*

*process has just made me stronger. I have to be the voice for my sons and that has taught me I can get what I want for my children if I am strong enough" (Participant 1).*

*"I wasn't around much in the beginning, I admit I was trying to avoid the autism, I think I was scared of it. Eventually I came round to it though and took responsibility for my sons. It was the greatest thing I could've done...I allowed myself to bond with them and now we have a great time together, its helped improve things for us all" (Participant 7).*

*"I see things like work differently now...I mean I enjoy it but I don't put it before all else like I maybe used to. In 20 years time, I'm not gonna be thinking about that important meeting or the people I worked with...I'm gonna be thinking about my child and how little things like his smile or getting a kiss mean the world to me...even if they are very sloppy kisses!" (Participant 4).*

#### **3.2.1.4.2 Summary and discussion of core category 'Reconstructing multiple identities and roles'**

In the process of adjustment, parents spoke about the ways in which they noticed changes in their roles and identities in the years since receiving a diagnosis for their child. For the majority, caregiving was an activity worth investing time and energy in. Indeed, the priorities of some mothers' changed, whereby they focused exclusively on the caregiving role. For some, this eventually led to feeling their lives had become an extension of their child's life, and caregiving as a defining feature of their self-identity. This could be related to feelings of a loss of independence and restriction in parents due to feeling unable to pursue their own goals. Indeed, parents of children with learning disability have been found to experience a variety of role adjustments, including lower career expectations, a sense of losing their own identity and a feeling of restriction (Heiman, 2002).

The centrality of the care-giving role also led some mothers to perceive other family member's needs as secondary to the child with disabilities. This could lead to difficulties within families; a finding also reflected in the literature concerning White families (e.g. Beresford, 1994). However, some mothers' sense of isolation in the caregiving role was reinforced by feeling unsupported by their husbands due to the influence of cultural factors. For example, some mothers attributed their isolation to cultural beliefs about men being socialised into believing child-care is the responsibility of mothers, and that males who shared in child-care responsibilities would be undermining their status as men.

Some mothers also spoke about the tension between focusing on the needs of the child and meeting the cultural expectations placed upon them in terms of fulfilling wider family obligations. Ahmad (1996) explains that an individuals' position in the family carries with it a complex of duties, rights, obligations and expectations, and that it is particularly important to Asian women to fulfill these duties if they are to maintain family honour and protect their moral reputation. Indeed, mothers in this study reported difficulties in letting go of the moral and emotional pressures exerted by family members to maintain cultural traditions. In those able to do this, it often resulted in tension and hostility.

Over time, some parents reported increasingly noticing dilemmas in wanting to do everything possible for their child and fulfilling their own needs; a dilemma widely reported elsewhere (e.g. Edelson, 2000; Thorin *et al.* 1996). However, some parents were eventually able to re-focus on their own identity needs and, as time passed, realised they could still achieve goals important to them as well as to their child and family as a whole. For some, this resulted in a shift over time in the centrality of the role played by the child with the disability in the structure of family life. This suggests that mothers were able to successfully 'border cross' (Peters, 1996) between different but interdependent roles and identities. The positive impact on emotional well-being of



being able to do this was clear from parents' accounts. However, for some parents, changes within the child led to a questioning of their priorities and could lead to a re-emergence of the centrality of the caring role.

Parents also noted other positive changes within themselves in terms of their values, perspectives, priorities, personalities and attitudes; perhaps reflecting the notion of perspectival and personal transformations as described by Scorgie and Sobsey (2000). The fact that some parents progressed and re-invented themselves over the years since the diagnosis seemed to imply conscious attention being given to the ways in which they constructed and managed their identities, both in relation to not only their own needs, but those of their child and family as well as cultural expectations. This finding relates to research examining adjustment across the life-span, which suggests that following periods of instability or stress, individuals undergo development and self-understanding in relation to managing identities, developing new skills, and coming to new realisations about themselves and the world (e.g. Breunlin, 1988; King *et al.* 2003).

### **3.3 Hypothesised model of the process of adjustment following a diagnosis**

In moving from a description of the core categories to hypothesising relationships between them, the researcher noticed that each of the categories could be seen to represent stages of a process of adjustment. For most of the parents, this process started once a diagnosis was received. Parents' descriptions seemed to suggest that they moved through various stages as represented by the core categories: accepting and understanding the diagnosis, to generating possibilities for action for the future, and re-evaluating their identities and roles. However, this process did not seem to occur in isolation. Parents' narratives appeared to suggest that, to varying degrees, the influence of contextual factors was significant in how they experienced these stages.

Therefore, based on the experiences of seven Pakistani Muslim parents, a hypothesised model is proposed to explain how the process of adjustment occurred. This model is shown in Appendix 12.

### **3.3.1 Discussion of hypothesised model**

Parents' accounts and the analysis suggested that once a diagnosis was received, a process began. The categories can be seen to broadly represent a linear process in the experience of parents adjusting to a diagnosis of learning disability and/or an ASD in their child. The model suggests that obtaining a diagnosis allows the process of adjustment to begin for parents by (consciously or unconsciously) moving through various stages, including constructing meanings, finding possibilities for future action, and reconstructing roles and identities. While these stages primarily occur at the individual level, they have been set within a framework of important contextual influences that appeared to influence the process of adjustment. These contextual influences include culture, religion, relationships with family/friends, professionals and wider society.

Obtaining a diagnosis is likely to influence how parents begin the process of constructing meanings. For example, the relationships established and communication with clinicians is likely to impact on the way that information about diagnoses is received and how it is used to arrive at meanings. In addition, the variations in emotional and cognitive reactions to diagnoses are likely to be related to the different interpretations that parents bring to the situation. This may be influenced by their own socially constructed set of knowledge regarding disability, as well as reflecting the interpretations brought forth by clinicians, family and friends and wider society. Constructions held by the self and others often had a cultural and religious focus.

Furthermore, receiving a certain diagnosis as opposed to an uncertain one appeared to affect the process of constructing meanings. It was interpreted that being able to construct meanings by arriving at an understanding of the diagnosis and their child, whilst assimilating and/or resisting the influence of others' constructions, allowed parents to move on to find possibilities for future action. Parents who had received an uncertain diagnosis were more likely to suspend the need to construct meanings until they received a more concrete diagnosis. However, this maintained feelings of not fully understanding their child and feeling unsure about how to move forward.

Parents who had received a certain diagnosis were required to re-evaluate the position of their child and of themselves as a parent in the process of constructing meanings. In doing so, difficulties often arose in relation to coping with an uncertain future. Generally, this uncertainty was mediated by creating new future images of their child and of their life as a family, with disability being an integral part of it. It was interpreted that being able to create new future images was an attempt to reduce feelings of anxiety about the future by aiming to attain realistic, yet hopeful visions of it. Indeed, it has been shown that the ability to make cognitive adjustments has been found to lessen the impacts of stress and challenges (Grant & Whittell, 2000).

However, when parents were unable to readily create new images, it appeared to be the case that there was a preoccupation with idealised images. Remaining preoccupied with these tended to maintain feelings of low mood, difficulty in accepting the diagnosis and moving on to find possibilities for future action. Indeed, it has been shown in the literature that parents who experience greater distress following a diagnosis engage in "wishful thinking", with the implication that greater distress is caused by being unable to accept the diagnosis and let go of previously held images (e.g. Knussen & Sloper, 1992). In addition, it was interpreted that for some parents the desire to 'live one day at a time' was a way to avoid possible disappointment and anxiety about the future.

It was interpreted that constructing meanings of the diagnosis and of their child was related to parents being able to generate possibilities for future action. Again, it seemed to be the case that doing this was driven by a need to control the outcome of an unpredictable future, as well as being driven by love and a wish to provide for their child. Some parents were constrained by difficulties in accessing and receiving culturally and linguistically appropriate services; this seemed to make the process of finding possibilities for future action more difficult.

With time and experience some parents came to regain a sense of control over their circumstances. It was felt that using social support as a coping strategy was key in allowing parents to regain a sense of control, reflected in the attendance at parent support groups for example. A sense of control seemed to be related to feelings of self-efficacy in parents, as well as being able to reach a stage of acknowledging and embracing the positive contributions of their children, whilst minimising limitations. Reaching this stage also seemed to involve a process whereby parents were able to re-evaluate their own identity needs and priorities as well as notice changes within themselves with respect to personal growth, values and attitudes. For some parents, the cultural expectations placed upon them in the wider family with respect to roles and identities maintained feelings of isolation and caregiving burden. Other mothers were able to garner strength to resist such cultural expectations when they were deemed to be at the expense of their emotional well-being or if they precluded being able to focus on their immediate families. It was interpreted that the challenges posed by receiving a diagnosis and adjusting to it, provided opportunities to grow personally. It was felt that rising to challenges and dealing with them successfully may allow an enhancement of feelings of parental self-efficacy. Taken together, this suggests that with time and experience, parents learn to not only adjust to their situation but also experience positive perceptions. This finding that positive perceptions can arise in spite of ongoing challenges relating to adjustment, is also related elsewhere in the literature (e.g. Scorgie et al. 1996).

It is likely that the nature of the process described is affected by a number of factors. For example, a parent receiving a second diagnosis after receiving a separate diagnosis a number of years ago may be less likely to experience the hypothesised stages in the same way the second time. For example, there may be less need to construct new meanings relating to having a child with a disability and, therefore, it may be easier for parents to more readily find possibilities for future action. It is hypothesised that in such cases parents may have already undergone a reconstruction of their roles and identities during the adjustment to the first diagnosis. In these cases, the need to endure the emotional and cognitive strains of a second adjustment process may not be as great. For some parents, it is hypothesised that this may relate to a greater emotional capacity to accumulate more positive perceptions than those parents who have not needed to undergo an adjustment process previously.

The ability for parents to adjust and cope are often viewed as traits that are independent from the circumstances and experiences that arise as a result of the child's disability. However, the present study provides support to the argument that parental responses, actions and adjustment evolve over time in response to specific experiences, such as interactions with services, family and wider society.

The researcher emphasises that the stages involved in the model outlined, as represented by the core categories, are not proposed as watertight stages. Rather than a strictly linear process, it is likely that the processes parents undergo following a diagnosis reappear at other developmental stages of both the child and the family. In addition, feelings of adjustment may fall away during periods of crisis or when new demands are placed on a family. When this happens, families are likely to have to revisit old meanings or construct new ones to allow a provision of a new range of choices. In this way, there is a sense of continually adapting over time and contexts, as represented by the bi-directionality between the core categories. This supports arguments that adjustment is not a strictly linear process and that it is necessary to view it in the context

of life events occurring in the family, the development of the child and changing resources of the family (e.g. Blacher, 1984). For example, while all the children in this study were under the age of 12, it is likely that new demands will be placed on families as the child enters adolescence, in light of the challenges known to be associated with adolescent development. Additionally, in the current study one parent's experience of undergoing a separation from her husband required her to not only re-evaluate her roles and identities but also construct new meanings and re-evaluate possibilities for action without the support of her husband.

Revisiting the literature which concerned predominantly White families showed that there is a substantial degree of overlap between the findings in the current study and those found elsewhere. For example, the stress and coping literature emphasises that recovery following a stressful event is predicated on the ability of the person to release old, inadequate meaning perspectives and formulate new perspectives that incorporate new identities and realities while maintaining belief in a hopeful outcome (e.g. Meichenbaum & Fitzpatrick, 1993). In addition, the core processes outlined in the current study relate to those suggested by the "parent transformation model" (Scorgie et al. 2004), as previously outlined.

Given this degree of overlap with existing literature, the current study tentatively supports the idea that the basic ways in which parents adjust to a diagnosis may be similar across cultures. Taken together, the current findings suggest that a universalist approach may be appropriate for considering cultural influences on the adjustment process of parents post-disclosure of diagnosis. As outlined previously, a universalist approach assumes that basic human characteristics are universal, and that culture influences the development and display of these characteristics. For example, cultural constructions of disability may vary across cultures and, therefore, influence the meaning-making processes that parents undergo; or the ability to reconstruct roles and

identities may be influenced by the cultural and familial obligations placed upon mothers.

## **CHAPTER 4      CONCLUSIONS**

This chapter will begin with a summary of the current research. Implications of the current findings for theory and clinical practice will then be outlined. Following this, a methodological critique will be provided. The current chapter will conclude with reflections of the researcher and participants in relation to the process of the research.

### **4.1      Summary of results**

Seven participants (five females and two males) took part in the current study. Each had a child who had a diagnosis of a learning disability and/or an ASD. The study adopted a qualitative research methodology, underpinned by a universalist stance. Grounded theory was the approach used to collect and analyse the data. Semi-structured interviews ranged in length from 30 minutes to 80 minutes and the researcher met with three participants on more than one occasion to collect data. The aim of the interviews was to explore South Asian parents' experiences of the diagnostic process for their child and the factors that may influence their subsequent understanding, acceptance and adjustment of the diagnosis and their child. The final sample consisted of one cultural group (Pakistani) who all identified themselves as being Muslims.

The current research generated four core categories. These related to the process of parental adjustment to a diagnosis of a learning disability and/or an ASD in their child. The first core category was called 'obtaining a diagnosis'. This related to the experiences of parents in battling for a diagnosis, receiving a diagnosis and their evaluations of the process. The second core category, 'constructing meanings', represented parents attempts to come to an understanding of the diagnosis once it was received. This involved various processes which appeared to be influenced by the meanings that others' brought to the diagnosis. The third core category, 'exploring possibilities for action', related to parents' attempts to manage the future by seeking strategies to help



their child and themselves, both at the formal and informal support level. The final core category 'reconstructing roles and identities', represented how parents' roles and identities changed over time and how they came to a position of re-evaluating these and reflecting on how they felt their experiences had changed them as people.

The core categories were formulated into a model outlining a process of parental adjustment following a disclosure of a diagnosis for their child. This model recognised that the categories 'constructing meanings', 'finding possibilities for action', and 'reconstructing roles and identities' as three broadly linear stages in moving towards adjustment to the diagnosis. The whole model was situated within various contextual factors. In other words, the process of adjustment was influenced by contextual factors such as culture, religion and relationships with family and friends, professionals and wider society. This highlights the complexity of the adjustment process.

## **4.2 Implications for current theoretical models and frameworks**

The study lends support to theoretical models of adjustment that recognise the challenges and disruption associated with parental adjustment to a child's diagnosis over time, while emphasising variability in parental responses (e.g. McCubbin & Patterson, 1983). In addition, it supports models which emphasise the potential for positive perspectives and resilience (e.g. Grant et al. 2007). Most models place a strong emphasis on adjustment as being the result of processes occurring at the individual level, with an emphasis on cognitive processes. While this study recognises the importance of such processes (as reflected in the core categories), the findings also point to the significance of contextual influence on these processes. For most parents, their experiences were set in cultural, religious and familial contexts. Whilst undertaken with a homogenous sample in terms of ethnicity and religion, incorporating an ethnic diversity focus while addressing issues of process may yield theoretical perspectives

applicable to diverse populations. This is an important starting point since most models of adjustment include no consideration of their cross-cultural applicability.

The current findings are one possible interpretation of the data and are bound by the context and conditions of the study. However, the model could be further tested prospectively in order to assess whether the steps offered take place as hypothesised, as well as allowing further exploration of the possible factors that impact on the various stages. Further testing across cultural groups and conditions would also allow the cross-cultural relevance of the model to be assessed. In addition, given that all of the parents in the current study had children aged 12 years or less, it would be interesting to test the model to examine the adjustment process of parents who receive diagnoses once their children have entered into adolescence, in order to explore whether there are any additional challenges.

### **4.3 Implications for practice**

The findings of this study are likely to corroborate what many health professionals already experience in clinical practice. The model can, therefore, provide a framework for reflecting on practice, improving relationships with parents and supporting families once a diagnosis has been disclosed.

The disclosure of diagnosis seemed to be important in facilitating the process of constructing meanings. However, for some parents language and communication barriers hampered the meanings they took from the disclosure process. Therefore, health professionals should be mindful of this and be proactive in facilitating clear and adequate communication with parents e.g. through the use of professional interpreters.

Professionals should take time to understand the beliefs parents hold about their diagnosis and the ways in which they come to make sense of it. They should be aware of

the various social, cultural and personal variables that might influence a parents' perception of disability and shape family outcome following diagnosis. Scorgie and Wilgosh (2006) recommend questions being asked such as "What do you know about autism?" or "Have you ever had any contact with a child with a learning disability?" in order to uncover beliefs and assumptions that might shape a parents response to, and adjustment to, the diagnosis of disability in their child.

In addition, since there was an emphasis on the importance of shared acceptance and understanding between parents, health professionals should undertake disclosure of diagnoses with both parents wherever possible. In addition, given that some parents spoke about negatively-focused cultural and/or religious constructions of disability being imposed on them by wider family members, clinicians could offer parents the opportunity to meet with other important family members. This could provide a way to dispel some of the cultural myths associated with disability and, hence, reduce the risk of mothers being blamed. The above points about the disclosure process are important in light of Hatton et al's. (2003) point that if disclosure and post-disclosure is conducted well, there can be important long-term benefits for families in terms of acceptance of their child and in mobilising formal and informal supports.

In light of the fact that parents constructions of meaning and acceptance of the diagnosis appeared to be influenced by the various professionals they come into contact with, it follows that clinicians should take a critical stance in examining their own beliefs and attitudes towards disability. This would require the recognition that we are all shaped by a particular culture that affects, both consciously and unconsciously, the way we think, feel and act. Additionally, clinicians should reflect on whether they may be imposing their own constructions of disability on parents, albeit inadvertently. This is important in light of evidence that clinicians' attempts to draw parents away from their individual systems of understanding by imposing their own understanding can cause confusion and lead to a break down of communication (Peters et al. 1998).

This model could also be used to engage in discussions with parents at the time of the disclosure. For example, some parents may find it useful to be aware of the commonality of the range of initial thoughts and feelings that parents often experience upon receiving a diagnosis. By classifying the responses that are found to be common, it reduces the possibility of these reactions being perceived as inappropriate or pathological in some way. It may also be helpful to outline the different ways other families have come to adjust e.g. by replacing lost images of their child, developing new understandings of their child and adjusting goals over time. Kearney (2001) suggests that by providing such anticipatory guidance, families can be helped to consider and obtain the resources and supports they may need to deal with challenges ahead.

However, it would need to be stressed that since each family is unique, it is highly unlikely that they will experience the stages in the same ways as other families. Emphasising that this is normal will avoid parents feeling that they ought to be experiencing the same process in the same way as other families, and if they aren't, that they are somehow not adjusting in the 'right way'. This requires a belief from professionals that stage models are only helpful if used flexibly and when they are firmly embedded and considered within the various levels of contextual influence on a family's life. In addition, professionals should be aware of cultural variations in South Asian families and should avoid viewing them as a homogenous group in terms of their responses to, and subsequent adjustment to, a diagnosis.

The current model could also be used to consider families who appear to have difficulty adjusting to the diagnosis. For example, assessing whether a parent has an adequate understanding of the disability in order to generate new images for the future or providing them with informed and supportive environments as a way to accrue possibilities for future action e.g. attendance at parent support groups. Taking a systemic view and considering the various stages proposed may also be helpful in addressing issues that appear, on the surface, to be related to resistance in following

advice. With some parents, re-conceptualising resistance as possible difficulties constructing meanings and, therefore, difficulties in finding possibilities for action, may provide a focus for intervention. This may include the provision of information to allow meanings to be constructed, as well as having discussions with the aim of fostering positive constructions, as well as increasing a parents' sense of competence in carrying out management strategies for their child. Indeed, fostering positive perceptions has been shown to be important for family well-being (Singer et al. 1999).

The question invariably arises about who is best placed to work with South Asian families? Health services operate within constrained budgets and there can be conflicts between limited personnel resources on one hand and absolute 'best practice' on the other (Summers & Jones, 2004). Therefore, this usually prevents the allocation of a specific health professional to specific families. In working with South Asian families, a South Asian professional may be likely to reflect upon their own experiences of belonging to an ethnic minority group and may potentially possess language skills relevant to different South Asian communities. However, it could be argued that this is not always necessary since it is unlikely that difficulties that may arise in South Asian families are due solely to issues of culture and religion.

#### **4.4 Methodological critique**

A number of methodological limitations can be identified in relation to the current study, particularly in relation to the application of grounded theory methodology.

##### **4.4.1 Literature review**

The researcher was aware of arguments that a researcher undertaking a grounded theory study should delay writing the formal literature review until later in the analysis process in order for it to be driven by emergent findings (e.g. Dallos & Vetere, 2005). Others argue that employing some deductive analysis, as influenced by existing

theories, is legitimate in a grounded theory study (e.g. Strauss & Corbin, 1998). In the current study, the researcher explored some of the key papers in the area in order to complete a research proposal. The researcher is aware that the current literature review focuses more broadly on the diagnostic process with some focus on subsequent adjustment, but is aware that the emergent findings would suggest that the review be more focused on processes of adjustment, if it were to be re-written. However, it can also be argued that since the researcher did not read numerous articles highly relevant to the adjustment processes of parents, there can be some confidence that the emergent findings are representative of the data and not derived from preconceived ideas from the evidence base. It can also be argued that any general concepts that were taken from the literature before undertaking analysis allowed the researcher to be sensitised to an initial understanding of the phenomena under investigation, as well as providing a point of departure from which to undertake interviews (Blumer, 1969).

#### **4.4.2 Sampling**

A further issue that arose concerned sampling. As previously outlined, grounded theory necessitates that theoretical sampling techniques are utilised in order to develop theory and achieve a saturation of themes. However, time constraints precluded an open-ended period of recruitment. Furthermore, the available sample of South Asian parents was small. This meant that there was a limited opportunity to select participants based on their ability to add further insight into the emerging themes. However, the researcher attempted to do this wherever possible e.g. recruiting male participants to provide insight into any possible areas of difference in the adjustment process between fathers and mothers.

However, on the whole, the researcher acknowledges that theoretical sampling and saturation are highly unlikely to have been achieved in this study. Certainly, the researcher was aware of arguments that achieving theoretical sampling and saturation is usually impractical for small studies due to time constraints (e.g. McCallin, 2003).

Indeed, there have been suggestions that a study may require up to 20 or 30 interviews before reaching a saturation of categories (e.g. Noerager-Stern, 2007) and that studying only one group will probably prevent theoretical saturation (Glaser & Strauss, 1967).

Instead, the present study aimed to achieve 'theoretical sufficiency' (Dey, 1999). Sufficient sampling is said to occur when "for the purposes of the study, a researcher demonstrates that a category offers sufficient depth and breadth of understanding about a phenomena, and relationships to other categories have been made clear" (Corbin & Strauss, 2008; p. 149). By grounding the categories in direct quotations and discussing the relationships between the categories, the reader will be able to judge whether a sufficient depth and breadth of understanding has been achieved for the purposes of the study. In addition, the researcher was aware of different ways in which theoretical sampling can be achieved outwith the sampling process. For example Dallos and Vetere (2005) suggest that theoretical sampling is also related to adapting and tailoring the semi-structured interview schedule in order to maximise understanding of the processes being discussed. Indeed, the researcher was aware that structure of the interview schedule evolved as the interviews progressed, reflecting an increasing understanding of the main issues being discussed.

Taking the above into account, it may be suggested that the present study was able to achieve theoretical sufficiency. Aiming for theoretical sufficiency seemed to provide a balance between the sampling methods as prescribed by grounded theory and the timing of interviews and availability of participants. With an open-ended period of data collection, the researcher could re-interview participants and recruit new participants to deepen understanding of the core categories and allow a greater degree of theoretical saturation to occur.

A further potential limitation of the study concerns possible bias in the recruitment of participants. The majority were recruited from a parent support group. Therefore, it



could be argued that they had all gotten (at least) to the stage of 'finding possibilities for action'. In addition, the majority of the parents had children with ASD diagnoses. Recruiting parents from different sources, across child disability diagnoses and with variation in the time since receiving a diagnosis, would provide further insight into the process of adjustment. Furthermore, the possibility of bias in recall is possible, whereby the narratives of parents who had received a diagnosis a number of years ago are likely to be influenced by their current thoughts and feelings, rather than being a wholly accurate representation of their experiences of the diagnosis and early stages of the adjustment process as they occurred. In addition, while the current study aimed to interview South Asian parents, the sample was homogenous in terms of religion (Islam) and ethnicity (Pakistani). Therefore, the potential to generalise to other South Asian groups is limited. However, the ability to generalise findings is not usually an intended aim of grounded theory studies; rather, its emphasis is on capturing the specificity of unique individual experiences (Strauss & Corbin, 1998).

In future studies it would be interesting to collate information on the socio-economic status and education levels of the population that was being sampled. This would allow the researcher to reflect further on the typicality of the current sample in relation to the population that it intended to represent. The researcher attempted to collect this information in relation to South Asian (and particularly Pakistani Muslim) parents who have children with learning disabilities and/or autism in Scotland and the rest of the UK. However, this information does not appear to be readily available to the best of the researcher's knowledge.

#### **4.4.3 Analysis**

Undertaking data analysis using a grounded theory approach requires that the researcher carries out initial coding and analysis of each transcript before further data collection. However, time limitations and the practicalities of carrying out interviews at convenient times for participants meant that the majority of the interviews were carried



out within a short time period, thus precluding full transcriptions and analysis being carried out between each interview. However, the researcher aimed to counter this limitation by familiarising herself as much as possible with the data between each interview by listening to recordings at least twice and noting down the themes that appeared to be emerging.

#### **4.4.4 Interviews**

The researcher believes that carrying out interviews over two appointments with three participants was beneficial in terms of adding to the richness of parents' narratives. While the reasons for doing this were mainly due to time constraints during the first interview, the researcher felt that these three participants were more relaxed at the second meeting and potentially more at ease in sharing their reflections with the researcher. Carrying out more than one interview also allowed the researcher to clarify important points from the first session as well as further explore emerging themes. Indeed, Charmaz (2006) encourages carrying out more than one interview as a way to add richness to participants' accounts.

### **4.5 Reflections on the present findings**

#### **4.5.1 Participant reflections**

Dallos and Vetere (2005) argue that qualitative research should allow the reader to hear not just the researcher's account of the phenomena in question, but also the participants own voices. Following the completion of each interview, the researcher asked about participants' experience of undertaking them. The researcher outlines their reflections on the interview process in her own research journal extract described later. Additionally, following the completion of the data analysis, it was important to seek validation of the findings from those who took part. The researcher undertook brief phone conversations with two participants who were available to discuss their reflections on the model developed.

One parent commented that the findings produced a new perspective on her experiences: *"It is an interesting way of looking at it, I haven't thought of it like that before but I don't think as parents we are always aware of the stages we go through after a diagnosis"* (Participant 4). This emphasised the fact that the stages proposed are not necessarily consciously experienced by parents. Another parent felt that the hypothesised model provided a good explanation of her experience. However, she also emphasised that the stages may not necessarily occur in the proposed sequence at all times for all parents, and that while she had achieved the stage of 'reconstructing roles and identities', other parents may not reach this stage for many years after a diagnosis (if at all): *"It would be important to remember it might not always work like that. I know a lot of parents who just live with the diagnosis...not really accepting it... they don't get to the stage of embracing it or their child...especially if they have really difficult circumstances...like being in a family that doesn't help"* (Participant 1). For the researcher this highlighted the need to remember that such models should not be used to stereotype parents and to look at the wider social context when considering the extent to which they have adjusted (or not). Although only carried out with a limited number of participants, the final member check generated good support for the present study's core categories and consequently the model outlining the process of adjustment.

Carrying out member checks in this way provides one way in which the reader can judge the dependability of findings. Other steps taken to ensure the dependability of findings included carrying important themes from earlier interviews into subsequent interviews as well as grounding the analysis in examples. Maintaining a research journal was another way in which the researcher sought to be open about the potential influence of her assumptions and beliefs. Once analysis was complete, the researcher examined the journal and found that a number of themes had emerged. The following section is written in the first person to reflect the language used throughout the journal.

#### 4.5.2 Researcher's reflections

One theme that emerged reflected my anxieties about adequately representing the experiences of the parents involved in the study. I worried that I wouldn't be able to do justice to the complexity of their experiences. This was coupled with anxieties about my inexperience in using a grounded theory approach. However, despite the vast nature of results usually obtained in qualitative studies, I rarely felt overwhelmed by this. I retained a sense of remaining close to the data and therefore feeling like I had a good understanding of what parents had shared with me. I noted that this felt to be in contrast to my experiences of doing quantitative research, where the reduction of data to numbers generally left me feeling somewhat distanced from my findings. In addition, I felt that my confidence increased as interviews progressed. In early interviews, I remained mindful of the tension between letting participants direct the interviews and feeling the need to gather "rich" data. However, as initial ideas arose in relation to the analysis, I felt more confident in broadly being able to maintain the required focus, whilst allowing participants to continue to influence the direction. In relation to the coding process, I tried to remain aware of the possibility that I may unconsciously force data into preconceived categories. Discussions with supervisors helped me to critically reflect on this issue and I frequently returned to the coding process, aiming to use labels for codes and categories that seemed to fit well with the data.

Another theme of my research journal concerned that of relationships and identities. Three participants made specific reference to their surprise at seeing an Asian psychologist and so I wondered whether my background might have influenced what they were sharing with me. Indeed, much has been written about 'insider research'. For example, concerns have arisen in relation to the lack of objectivity associated with research conducted with populations with which the researcher self-identifies (e.g. Asselin, 2003). However, others have argued that researchers should have substantial familiarity with the client group or phenomena under investigation if they are to avoid

missing crucial information or pursuing unimportant leads (e.g. Gubrium, 1994; Hatton, 2004).

I felt that my own ethnic and religious background facilitated establishing rapport with the participants and that they valued having a shared knowledge of some of the cultural and religious issues being discussed. However, it was difficult to maintain a naïve position and not to assume that I had a full understanding. I felt participants were puzzled when I needed clarification on certain religious or cultural constructs. I noticed a tension between wanting to remain an 'insider' and being open about being unfamiliar with certain religious or cultural constructs. I wondered if asking for clarification might place me as a member of the 'eurocentric' system which some parents had mentioned didn't understand them. In these cases, I saw how being a "cultural stranger" (i.e. being of a different background to participants) might avoid a tension and wariness about clarifying aspects of culture or religion that participants might expect to remain implicit and unspoken between two members of the same background (Hatton, 2004).

Further thoughts within my journal on the theme of identities related to being aware of the difficulty of splitting from my professional identity as a trainee clinical psychologist working for the NHS. Working clinically in the same area made me aware that I was, at times, being placed in an 'expert role'. This was reflected in occasional queries from parents in how, for example, they could manage difficult child behaviours. I was keen to avoid this role and aimed to empower parents in the research process by reinforcing their position as experts on their own child.

I found that as I got to know parents (especially those who I met on more than one occasion) and when I let go of my sense of being an objective researcher, I came to feel a sense of involvement in, and obligation, for their well-being. This was reinforced by reflections made by participants about the value they found in our interactions. For example, reflections from two separate parents included *"Talking with you has really let*

*me let of some steam"* and *"My heart feels lighter after this interview"* (participant 1 and 4 respectively). This made me reflect on the fact that I was clearly an integral part of the research process and it demonstrated the social processes involved in constructing data. This reminded me of Steier's (1991) comment that "taking reflexivity seriously in doing research is marked by a concern for recognising that constructing is a social process, rooted in language, not inside one's head" (Steier, 1991; p.5).

From my perspective at the end of the research process, it felt as though parents had allowed me to join them in a exploration of their own experiences and that the relationships constructed with them and the questions I asked merely acted as catalysts for this process.

#### **4.6 Concluding thoughts**

The present study has outlined a model to account for the experiences of seven South Asian parents in relation to the process of adjustment to a diagnosis of a learning disability and/or an ASD. This has been embedded within important contextual factors which seemed to have a bearing on the way that parents adjusted. By incorporating a diversity focus, the researcher aimed to ensure that ethnic background, experiences and perspectives were valued, rather than assumed to be unimportant and, therefore, marginalised. One parent summed up the value of retaining a diversity focus:

*"We have lots in common with White families when it comes to raising a child with a disability...but that doesn't mean we are the same...my culture, my religion does play an important part in my life. It has a big influence on the kind of parent I am and how I deal with things. Our family wouldn't be us without our culture and religion"*  
(Participant 5).

## References

- Abbeduto, L., Seltzer, M.M., Shattuck, P.T., Krauss, M.W., Orsmond, G.I., & Murphy, M.M. (2004). Psychological well-being and coping in mothers of adolescents and adults with developmental disabilities: Comparisons between autism, Down syndrome and fragile-X syndrome. *American Journal on Mental Retardation*, 109, 237-254.
- Ahmad, W. (1996). Consanguinity and related demons: science and racism in the debate on consanguinity and birth outcome. In: C. Samson. & N. South (Eds.) *Researching Cultural Difference in Health*. London: Routledge.
- Ahmad, W. & Atkin, K. (1996). *'Race' and Community Care*. Buckingham: Open University Press.
- Aitken, G. (1998). Reflections on working with and across differences. Race and professional differences in clinical psychology therapy encounters. *Clinical Psychology Forum*, 118, 11-17.
- American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of the Mental Disorders* (4<sup>th</sup> Edition). Washington, DC: American Psychiatric Association.
- Asselin, M.E. (2003). Insider research: issues to consider when doing qualitative research in your own setting. *Journal for nurses in Staff Development*, 19(2), 99-103.
- Atkin, K. & Ahmad, W. (2000). Family caregiving and chronic illness: how parents cope with a child with sickle cell disorder or thalassaemia. *Health and Social Care in the Community*, 8(1), 57-69.
- Azmi, S., Emerson, E., Caine, A. & Hatton, C. (1996). *Improving Services for Asian People with Learning Disabilities and Their Families*. Hester Adrian Research Centre/The Mental Health Foundation: Manchester.
- Bailey, D.B., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M.E., Rodriguez, P., Vazquez-Montilla, E. & Skinner, M. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation*, 104, 437-451.
- Banis, J. & Jones, A (2003). Do cognitive assessments lead to change for people with intellectual disabilities? *Clinical Psychology*, 23, 19-22.
- Barker, C., Pistrang, N. & Elliot, R. (2002). *Research methods in clinical psychology: An introduction for students and practitioners* (2<sup>nd</sup> Ed.). Chichester: Wiley.

- Baxter, C., Poonia, K., Ward, L. & Nadirshaw, Z. (1990). *Double Discrimination. Issues and Services for People with Learning Difficulties from Black and Ethnic Minority Communities*. King's Fund Centre and the Commission for Racial Equality, London.
- Bazeley, P. (2007). *Qualitative Data Analysis with NVivo*. London: Sage Publications.
- Beresford, B. (1994). Resources and strategies: how parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 35, 171-209.
- Berry, J.W. (1995). Psychology of acculturation. In N.R. Goldberger & J.B. Veroff (Eds.) *The Culture and Psychology Reader*, pp. 457-488. New York: New York University Press.
- Berry, J.W. (1999). On the unity of the field of culture and psychology. In: J. Adamopoulos & Y. Kashima (Eds.) *Social Psychology and Cultural Context*, pp. 7-15. London: Sage.
- Berry, J.W., Poortinga, Y.H., Segall, M.H. & Dasen, P.R. (2002). *Cross-Cultural Psychology: Research and Applications*, 2<sup>nd</sup> edition. Cambridge: Cambridge University Press.
- Betancourt, H. & Lopez, S.R. (1995). The study of culture, ethnicity and race in American psychology. In N.R. Goldberger & J.B. Veroff (Eds.) *The Culture and Psychology Reader*, pp. 87-107. New York: New York University Press.
- Bhaumik, S., Branford, D., McGrother, C. & Thorp, C. (1997). Autistic traits in adults with learning disabilities. *British Journal of Psychiatry*, 170, 502-506.
- Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: fact or artefact. *Mental Retardation*, 22, 55-68.
- Blacher, J. (2001). Transition to adulthood: mental retardation, families and culture. *American Journal on Mental Retardation*, 106, 173-188.
- Blacher, J., & Baker, B.L. (2007). Positive impact of intellectual disability on families. *American Journal on Mental Retardation*, 112, 375-391.
- Blacher, J. Hatton, C. (2007). Families in context: Influences on coping and adaptation. In: S.L. Odom., R.H. Horner., Snell, M.E. & Blacher, J. (Eds.) *Handbook of Developmental Disabilities* (pp.531-551). New York: The Guildford Press.
- Blacher, J. & McIntyre, L.L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact. *Journal of Intellectual Disability Research*, 50(3), 184-198.
- Blacher, J. & Mink, I.T. (2004). Interviewing family members and care providers: Concepts, methodologies and cultures. In: E. Emerson, C. Hatton, T. Thompson, & T. Parmenter (Eds.) *International handbook of applied research in intellectual disabilities* (pp. 133-159). Chichester, UK: Wiley.



- Blacher, J., Shapiro, J., Lopez, S., Diaz, L. & Fusco, J. (1997). Depression in Latina mothers of children with mental retardation: a neglected concern. *American Journal on Mental Retardation*, 101, 483-496.
- Blumer, H. (1969). *Symbolic interactionism*. Englewood Cliffs, NJ: Prentice Hall.
- Bogdan, R. & Taylor, S. (1976). The judged not the judges: an insider's view of mental retardation. *American Psychologist*, 31, 47-52.
- Bostock, J. & Diamond, B. (2005). The value of community psychology: Critical reflections from the NHS. *Clinical Psychology Forum*, 153, 22-25.
- Boyчук, J. E., & Morgan, D. (2004). Grounded theory: reflections on the emergence vs. forcing debate. *Journal of Advanced Nursing*, 48(6), 605-612.
- Breunlin, D. (1988). Oscillation theory and family development. In: C.J. Falicov (Ed.) *Family transitions* (pp. 113-155). Guilford: New York.
- British Psychological Society (2000a). *Learning Disability: Definitions and Contexts*. Leicester: British Psychological Society.
- British Psychological Society (2000b). *Code of Conduct, Ethical Principles and Guidelines*. Leicester: British Psychological Society.
- Brogan, C.A. & Knussen, C. (2003). The disclosure of a diagnosis of an autistic spectrum disorder. *Autism*, 7, 31-46.
- Butt, J. & Mirza, K. (1996). *Social Care and Black Communities*. London: HMSO.
- Bywaters, P., Ali, Z., Fazil, Q., Wallace, L. & Singh, G. (2003). Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: Considerations for service providers and the disability movement. *Health and Social Care in the Community*, 11(6), 502-509.
- Chamba, R., Ahmad, W., Hirst, M., Lawton, D. & Beresford, B. (1999). *On the Edge: minority ethnic families caring for a severely disabled child*. Policy Press: Bristol.
- Channabasavanna, S.M., Bhatti, R.S. & Prabhu, L.R. (1985). A study of attitudes of parents towards the management of mentally retarded children. *Child Psychiatry Quarterly*, 18(2), 44-47.
- Charmaz, K. (2003a). Grounded Theory: Objectivist and Constructivist Methods. In N.K. Denzin & Y.S. Lincoln (Eds.). *Strategies of Qualitative Inquiry* (2<sup>nd</sup> edition., pp. 249-291). Thousand Oaks, CA: Sage Publications.



- Charmaz, K. (2003b). Qualitative Interviewing and Grounded Theory Analysis. In J.A. Holstein & J.F. Gubrium (Eds.). *Inside Interviewing: New lenses, new concerns* (pp. 311-330). Thousand Oaks, CA: Sage Publications.
- Charmaz, K. (2006). *Constructing Grounded Theory: A practical guide though qualitative analysis*. London: Sage Publications.
- Coleman, G., Fatimilehin, I. & Gohil, K. (2007). *Winning the battle: Consultation on the views and needs of families of disabled Black and ethnic minority children in Liverpool*. The Building Bridges Service: Liverpool.
- Connor, I. (2005). *It's about mair than who uh kiss : a grounded theory approach to sexual identity and identity development in adolescence*. Unpublished doctoral thesis, University of Edinburgh, Edinburgh.
- Conrad, P. & Potter, D. (2000). From hyperactive children to ADHD adults: observations on the expansion of medical categories. *Social Problems*, 47, 559-582.
- Coonrod, E.E. & Stone, W.L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants and Young Children*, 17(3), 258-268.
- Corbin, J. & Strauss, A. (2008). *Basics of qualitative research 3e: techniques and procedures for developing grounded theory*. Sage Publications: London.
- Cottrell, D.J. & Summers, K. (1990). Communicating an evolutionary diagnosis of disability to parents. *Child: Care, Health and Development*, 16, 211-218.
- Croot, E.J., Grant, G., Cooper, C.L. & Mathers, N. (2008). Perceptions of the causes of childhood disability among Pakistani families living in the UK. *Health and Social Care in the Community*, 16(6), 606-613.
- Cross, T., Bazron, B., Dennis, K., & Isaacs, M. (1989). *Towards a culturally competent system of care: A monograph on effective services for minority children who are severely emotionally disturbed*. Washington, DC: Georgetown University Child Development Center.
- Cunningham, C. (1994). Telling parents their child has a disability. In: P. Mittler. & H. Mittler. (Eds.) *Innovations in family support for people with learning disabilities*. Whittle-le-Woods: Lisieux Hall.
- Cunningham, C., Morgan, P. & McGucken, R. (1984). Down's syndrome: Is dissatisfaction with disclosure of diagnosis inevitable? *Developmental Medicine and Child Neurology*, 26, 33-39.
- Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31, 1476-1484.

Daily, D.K., Ardinger, H.H. & Holmes, G.E. (2000). Identification and evaluation of mental retardation. *American Family Physician*, 61, 1059-1067.

Daley, T. (2004). From symptom recognition to diagnosis: Children with autism in urban India. *Social Science in Medicine*, 58, 1323-1355.

Dallos, R. and Vetere, A. (2005) *Research Methods in Psychotherapy*, Maidenhead : McGraw -Hill/Open University Press.

David, R., & Whitehouse, J. (1998). Modelling the consultation process in a secondary referral unit for children. *International journal of language & communication disorders / Royal College of Speech & Language Therapists. International Journal of Communication Disorders* (33) Suppl, 532-537.

Dey, I. (1999). *Grounding Grounded Theory. Guidelines for Qualitative Inquiry*. Academic Press. San Diego: CA.

Di Terlizzi, M., Cambridge, P. & Maras, P. (1999). Gender, ethnicity and challenging behaviour: a literature review and exploratory study. *Tizard Learning Disability Review*, 4, 33-44.

Drapeau, M. (2002). Subjectivity in research; Why not? But...*The Qualitative Report*, 7(3), 1-20.

Dyches, T.T., Wilder, L.K., Sudweeks, R.R., Obiakor, F.E. & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders*, 34(2), 211-222.

Edelson, M. (2000). *My journey with Jake: A memoir of parenting and disability*. Between the Lines. Toronto: ON.

Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, 47(4), 385-399.

Emerson, E. (2004). Poverty and children with intellectual disabilities in the world's richer countries. *Journal of Intellectual and Developmental Disability*, 29, 319-337.

Emerson, E., Azmi, S., Hatton, C., Caine, A., Parrott, R. & Wolstenholme, J. (1997). Is there an increased prevalence of severe learning disabilities among British Asians? *Ethnicity and Health*, 2, 317-321.

- Emerson, E., Fujiura, G. T. & Hatton, C. (2007). International perspectives. In S.L. Odom, R.H. Horner, M. Snell & J. Blacher (Eds) *Handbook on Developmental Disabilities*, 593-613. New York: Guilford Press.
- Emerson, E., Graham, H., Hatton, C. (2006). The measurement of poverty and socio-economic position in research involving people with intellectual disability. In: Glidden, I.M. (Ed.) *International Review of Research in Mental Retardation* (pp 77-109). New York: Academic Press.
- Emerson, E. & Hatton, C. (1999). Future trends in the ethnic composition of British society and among British citizens with learning disabilities. *Tizard Learning Disability Review*, 4, 28-32.
- Emerson, E. & Robertson, J. (2002). *An analysis of the Current and Future Needs of South Asian and Black Children with Learning Disabilities in Birmingham*. Institute for Health Research. Lancaster University: Lancaster.
- Emerson, E., Robertson, J. & Wood, J. (2004). Levels of psychological distress experienced by family carers of children and adolescents with intellectual disabilities in an urban conurbation. *Journal of Applied Research in Intellectual Disabilities*, 17, 77-84.
- Erlandson, D. A., Harris, E. L., Skipper, B. L., & Allen, S. D. (1993). *Doing naturalistic inquiry*. Newbury Park, CA: Sage.
- Fatimilehin, I.A. & Nadirshaw, Z. (1994). A cross-cultural study of parental attitudes and beliefs about learning disability (mental handicap). *Mental Handicap Research*, 7(3), 202-227.
- Fazil, Q., Bywaters, P., Ali, Z., Wallace, L. & Singh, G. (2002). Disadvantage and discrimination compounded: the experience of Pakistani and Bangladeshi parents of disabled children in the UK. *Disability and Society*, 17(3), 237-253.
- Ferguson, P. (2001). Mapping the family: Disability studies and the exploration of parental response to disability. In: G.L. Albrecht, K.D. Seelman, & M. Bury (Eds.) *Handbook of disability studies* (pp. 373-395). Thousand Oaks: Sage.
- Flynt, S.W. & Wood, T.A. (1989). Stress and coping of mothers of children with moderate mental retardation. *American Journal on Mental Retardation*, 94, 278-283.
- Fourie, R.J. (2008). *A Grounded theory study of the therapeutic relationship in speech and language therapy*. Unpublished doctoral thesis, National University of Ireland, Eire.
- Friedman, T. (2006). *The world is flat: A brief history of the twenty first century*. New York: Farrar, Strauss & Giroux.

- Fryers, T. (1993). Epidemiological thinking in mental retardation: Issues in taxonomy and population frequency. *International Review of Research in Mental Retardation*, 19, 97-133.
- Fujiura, G. (1998). Demography of family households. *American Journal of Mental Retardation*, 103, 225-235.
- Fujiura, G.T. & Yamaki, K. (1997). Analysis of ethnic variations in developmental disability prevalence and household economic status. *Mental Retardation*, 35, 286-294.
- Fujiura, G. & Yamaki, K. (2000). Trends in demography of childhood poverty and disability. *Exceptional Child*, 66, 187-199.
- Gilbert, P., Gilbert, J. & Sanghera, J. (2004). A focus group exploration of the impact of Izzat, shame, subordination and entrapment on mental health and service use in South Asian women living in Derby. *Mental Health, Religion & Culture*, 7(2), 109-130.
- Glaser, B. G. (1978). *Theoretical Sensitivity: Advances in the Methodology of Grounded theory*. Mill Valley, Ca.: Sociology Press.
- Glaser, B.G. & Strauss, A. L. (1965). *Awareness of dying*. Chicago: Aldine.
- Glaser, B.G. & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine: Chicago.
- Goin-Kochel, R.P., MacKintosh, V.H. & Myers, B.J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism*, 10, 439-451.
- Goldberg, D. & Williams, P. (1988). *A Users' Guide to the General Health Questionnaire*. Windsor: NFER-Nelson.
- Good, M., Good, B. & Munakato, T. (1994). Oncology and narrative time. *Social Science in Medicine*, 855-862.
- Grant, G. (1990). Elderly parents with handicapped children.: anticipating the future. *Journal of Aging Studies*, 4, 359-374.
- Grant, G., Ramcharan, P. & Flynn, M. (2007). Resilience in families with children and adult members with intellectual disabilities: tracing elements of a psycho-social model. *Journal of Applied Research in Intellectual Disabilities*, 20, 563-575.
- Grant, G. & Whittell, B. (2000). Differentiated coping strategies in families with children and adults with intellectual disabilities: the influence of gender, family composition and the lifespan. *Journal of Applied Research in Intellectual Disabilities*, 13, 256-275.

- Graungaard, A.H. & Skov, L. (2006). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development*, 33, 3, 296-307.
- Gray, D. (1994). Coping with autism: stresses and strategies. *Sociology of Health and Illness*, 16, 275-300.
- Gray, D. (1995). Lay conceptions of autism: Parents' explanatory models. *Medical Anthropology*, 16, 99-118.
- Green, S.E. (2002). Mothering Amanda: Musings on the experience of raising a child with cerebral palsy. *Journal of Trauma and Loss*, 7, 21-34.
- Gubrium, J.F. (1994). Interviewing. In: B.F. Crabtree., W.L. Miller., R.B. Addison., V.J. Gilchrist. & A. Kuzel (Eds.) *Collaborative Research in Primary Care*, (pp.65-76). Thousand oaks, CA: Sage publications.
- Hall, W. A. and Callery, P. (2001) Enhancing the rigor of grounded theory: incorporating reflexivity and relationality. *Qualitative Health Research*, 11(2), 257-272.
- Hall, D. & Hill, P. (1996). *The child with a disability, second edition*. Blackwell Science: Oxford.
- Harris, S.L. (1996). Servicing families of children with developmentally disabilities: Reaching diverse populations. *Special Services*, 12, 79-86.
- Harry, B. (1992). An ethnographic study of cross-cultural communications with Puerto Rican-American families in the special education system. *American Educational Research Journal*, 29, 471-494.
- Hasnat, M.J. & Graves, P. (2000a). Disclosure of developmental disability: A study of parent satisfaction and the determinants of satisfaction. *Journal of Paediatric Child Health*, 36, 32-35.
- Hasnat, M.J. & Graves, P. (2000b). Disclosure of developmental disability: A study of paediatricians' practices. *Journal of Paediatric Child Health*, 36, 27-31.
- Hassall, R., Rose, J. & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49, 405-418.
- Hastings, R.P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual and Disability Research*, 47, 231-237.

- Hastings, R.P., Allen, R., McDermott, K. & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 269-275.
- Hastings, R.P. & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal of Mental Retardation*, 107, 222-232.
- Hastings, R.P. & Taunt, H. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, 107, 116-127.
- Hastings, R.P., Sonuga-Barke, E.J. & Remington, B. (1993). An analysis of labels for people with learning disabilities. *British Journal of Clinical Psychology*, 32, 463-465.
- Hatton, C. (2002). People with intellectual disabilities from ethnic minority communities in the US and the UK. *International Review of Research in Mental Retardation*, 25, 1-55.
- Hatton, C. (2004). Cultural Issues. In E. Emerson, C. Hatton, T. Thompson, & T. Parmenter (Eds.). *Applied research in intellectual disabilities* (pp. 41-60). West Sussex, UK: Wiley.
- Hatton, C., Akram, Y., Robertson, J., Shah, R. & Emerson, E. (2003). The disclosure process and its impact on South Asian families with a child with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 177-188.
- Hatton, C., Akram, Y., Shah, R., Robertson, J. & Emerson, E. (2002). *Supporting South Asian Families with a Child with Severe Disabilities*. Jessica Kinglsey Publishers: London.
- Hatton, C., Azmi, S., Caine, A. & Emerson, E. (1998). Informal carers of adolescents and adults with learning difficulties from the South Asian communities: family circumstances, service support and carer stress. *British Journal of Social Work*, 28, 821-837.
- Heiman, T. (2002). Parents of children with disabilities: resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities*, 14, 159-171.
- Helman, C. (2000). *Culture Health and Illness*. Butterworth-Heinemann: London.
- Henwood, K. & Pidgeon, N. (1992). Qualitative research and psychological theorizing. *British Journal of Psychiatry*, 83, 97-111.
- Howie-Davies, R. & McKenzie, K (2007). Diagnosis, information and stress in parents of children with a learning disability. *Learning Disability Practice*, 10(8), 28-33.
- Howlin, P. & Asgharian, A. (1999). The diagnosis of autism and Asperger's syndrome: findings from a survey of 770 families. *Developmental Medicine and Child Neurology*, 41, 834-839.



Howlin, P. & Moore, A. (1997). Diagnosis in Autism: A survey of 1200 patients in the UK. *Autism*, 1, 135-162.

Howlin, P. (1998). *Children with Autism and Asperger Syndrome: A Guide for Practitioners and Carers*. Chichester: Wiley.

Hughes, J.M (1984). Some selected attitudes to mental retardation in developed and developing countries. *Mental Handicap Bulletin*, 53.

Hyman, S.L., Rodier, P.M. & Davidson, P. (2001). Pervasive developmental disorders in young children. *Journal of the American Medical Association*, 285, 3093-3099.

Janesick, V. (2003). The choreography of qualitative research design: Minuets, improvisations, and crystallization. In N.K. Denzin & Y.S. Lincoln (Eds.). *Collecting and interpreting qualitative materials* (2<sup>nd</sup> edition, pp 199-258). Thousand Oaks, CA: Sage Publications.

Jenkins, R. (1998). *Questions of Competence: Culture, classification and intellectual disability*. Cambridge: Cambridge University Press.

Jones, M. & Devlin, W. (2009). Clinical psychologists' experiences and views of undertaking psychological therapies with clients from Black and minority ethnic communities. *Clinical Psychology Forum*, 195, 15-18.

Kan, M. M., & Parry, K. W. (2004). Identifying paradox: A grounded theory of leadership in overcoming resistance to change. *The Leadership Quarterly*, 15(4), 467-491.

Katbamna, S., Parker, G., Ahmad, W. & Baker, R. (1998). *Experiences and needs of carers from the South Asian communities*. University of Leicester: Nuffield Community Care Studies Unit.

Kausar, S., Jevne, R. & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal of Developmental Disabilities*, 10, 35-46.

Kearney, M. (2001). Focus on research methods: levels and applications of qualitative research evidence. *Research on Nursing and Health*, 24, 145-153.

King, G., Cathers, T., Brown, E., Specht, J., Willoughby, C., Miller-Polgar, J., MacKinnon, E., Smith, L. & Havens, L. (2003). Turning points and protective processes in the lives of people with chronic disabilities. *Qualitative Health Research*, 13, 184-206.

Klingner, J.K., Blanchett, W. & Harry, B. (2007). Race, Culture, and Developmental Disabilities. In: S.L. Odom., R.H. Horner., Snell, M.E. & Blacher, J. (Eds.) *Handbook of Developmental Disabilities* (pp.55-75). New York: The Guildford Press.

- Klotz, J. (2004). Sociocultural study of intellectual disability: moving beyond labelling and social constructionist perspectives. *British Journal of Learning Disabilities*, 32, 93-104.
- Knussen, C. & Sloper, P. (1992). Stress in families of children with disability: a review of risk and resistance factors. *Journal of Mental Health*, 1, 241-257.
- Landsman, G.H. (2003). Emplotting children's lives. *Social Science in Medicine*, 56, 1947-1960.
- Leyin, A. (2004). Should we abandon the concept of mild learning disability? A response. *Clinical Psychology*, 41, 27-42.
- Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Lipton, H.L. & Svarstad, B. (1977). Sources of variation in clinicians communication to parents about mental retardation. *American Journal of Mental Deficiency*, 2, 155-161.
- Lord, C. & Spence, S. (2006). Autism spectrum disorders: phenotype and diagnosis. In: S.O. Moldin. & J.L.R. Rubenstein. (Eds.) *Understanding Autism: Basic Neuroscience to Treatment* (pp. 1-23). New York: CRC Taylor and Francis.
- Magana, S. M. (2000). Mental retardation research methods in Latino communities. *Mental Retardation*, 38, 303-315.
- Magana, S.M. (1999). Puerto Rican families caring for an adult with mental retardation: Role of familism. *American Journal on Mental Retardation*, 104, 466-482.
- Mandell, D.S., Listerud, J., Levy, S.E. (2002). Race differences in the age of diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41, 1447-1453.
- Manning, P.K. & Cullum-Swan. (1994). Narrative, Content, and Semiotic Analysis. In: N.K. Denzin. & Y.S. Lincoln (Eds.). *Handbook of Qualitative Research* (pp. 463-479). Thousand Oaks: Sage Publications.
- Mansell, W. & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: access to information and use of services. *Autism*, 8, 387-407.
- Mary, N.L. (1990). Reactions of Black, Hispanic, and White mothers to having a child with handicaps. *Mental Retardation*, 28, 1-5.
- Maxwell, J. A. (1996). *Qualitative Research Design: An Interactive Approach* (Vol. 41). London: Sage.



- McCallin, A. M. (2003). Designing a grounded theory study: some practicalities. *Nursing in Critical Care*, 8(5), 203-208.
- McCubbin, H. & Patterson, J. (1983). The family stress process: The double ABCX model of family adjustment and adaptation. *Marriage and Family Review*, 6, 7-37.
- McCubbin, H., McCubbin, M. & Thompson, A. (1993). Resiliency in families: the role of family schema and appraisal in family adaptation to crises. In: T.H. Brubaker (Ed.) *Family Relations: Challenges for the Future* (pp. 153-177). Sage: Newbury Park, CA.
- McGrother, C.W., Bhaumik, S., Thorp, C.F., Watson, J.M. & Taub, N.A. (2002). Prevalence, morbidity and service need among South Asian and white adults with intellectual disability in Leicestershire, UK. *Journal of Intellectual Disability Research*, 46(4), 299-309.
- McLaughlin, J. (2005). Exploring diagnostic processes: social science perspectives. *Archives of Disease in Childhood*, 90, 284-287.
- Meichenbaum, D. & Fitzpatrick, D. (1993). A constructivist narrative perspective on stress and coping: stress inoculation applications. In: L. Goldberger. & S. Breznitz, S. (Eds.) *Handbook of Stress: Theoretical and Clinical Aspects* (pp. 706-723). New York: Free Press.
- Midence, K. & O'Neill, M. (1999). The experience of parents in the diagnosis of autism: a pilot study. *Autism*, 3, 273-285.
- Mir, G., Nocon, A., Ahmed, W. & Jones, L. (2001). *Learning Difficulties and Ethnicity*. London: Department of Health.
- Mirza, I., Tareen, A., Davidson, L.L. & Rahman, A. (2009). Community management of intellectual disabilities in Pakistan: a mixed methods study. *Journal of Intellectual Disability Research*, 53(6), 559-570.
- Mishler, E. (1986). *Research interviewing: context and narrative*: Cambridge, MA: Harvard University Press.
- Modood, T., Berthoud, R., Lakey, J., Nazroo, J., Smith, P., Virdee, S. & Belshom, S. (1997). *Ethnic Minorities in Britain: Diversity and Disadvantage*. London: Policy Studies Institute.
- Mohr, J. J. (1996). The management and control of information in high-technology firms. *The Journal of High Technology Management Research*, 7(2), 245-268.
- Morris, J. (1993). Gender and disability. In: J. Swain, V. Finkelstein, S. French & M. Oliver (Eds.) *Disabling Barriers, Enabling Environments* (pp. 85-92). London: Sage.

- Morse, J. (1999a). Myth#93: reliability and validity are not relevant to qualitative inquiry. *Qualitative Health Research*, 9, 717-718.
- Morse, J. (1999b). Silent debates in qualitative inquiry. *Qualitative Health Research*, 9, 13-14.
- Mpofu, E. (2002). Psychology in sub-Saharan Africa: challenges, prospects and promises. *International Journal of Psychology*, 37, 179-186.
- Mühr, T. (1997). *Atlas TI*. Berlin: Scientific Software Development.
- Mundy, P. Crowson, M. (1997). Joint attention and early social communication: implications for research on intervention with autism. *Journal of Autism and Developmental Disorders*, 27, 653-676.
- Murray, G.C., McKenzie, K. & Lindsay, W.R. (2003). A pilot study of the use of the WAIS III with people with a learning disability. *Clinical Psychology*, 28, 17-21.
- Neely-Barnes, S. & Macenko, M. (2004). Predicting impact of childhood disability on families: results from the 1995 National Health Interview Survey Disability Supplement. *Mental Retardation*, 42(4), 284-293.
- Neely-Barnes, S.L. & Dia, D.A (2008). Families of children with disabilities: a review of literature and recommendations for interventions. *Journal of Early and Intensive Behaviour Intervention*, 5(3), 93-107.
- Nettleton, J., & Reilly, O. (1998). Facilitating effective learning during clinical placement. *International Journal of Language and Communication Disorders*, 33 Suppl: 250-254.
- Nickel, R. (1996). Controversial therapies for young children with developmental disabilities. *Infants and Young Children*, 8, 29-40.
- Noerager-Stern, P. (2007). On solid ground: essential properties for growing grounded theory. In: A. Bryant & K. Charmaz (Eds.) *The SAGE Handbook of Grounded Theory* (pp. 114-127). Sage Publications: London.
- Nota, L., Soresi, S., Ferrarai, L., Wilgosh, L. & Scorgie, L. (2003). Life management and quality of life of parents of children with diverse disabilities. *Developmental Disabilities Bulletin*, 31, 155-181.
- O'Hara, J. (2003). Learning disabilities and ethnicity: achieving cultural competence. *Advances in Psychiatric Treatment*, 9, 166-176.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Work*, 43, 190-193.

- Olsson, M. Hwang, C. (2002). Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disabilities Research*, 46, 548-559.
- Patel, M. (1998). Black therapists and cross-cultural therapy: issues of power dynamics and identity. *Clinical Psychology Forum*, 114, 13-15.
- Pearson, P., Simms, K., Ainsworth, C. & Hill, S. (1999). Disclosing special needs to parents. Have we got it right yet? *Child: Care, Health and Development*, 25, 3-14.
- Peters, S. (1996). The politics of disability identity. In: L. Barton (Ed.) *Disability and Society: Emerging issues and insights* (pp. 215-234). Addison Wesley Longman: Harlow.
- Peters, S., Stanely, I., Rose, M. & Salmon, P. (1998). Patients with medically unexplained symptoms: sources of patients' authority and implications for demands on medical care. *Social Science & Medicine*, 46, 559-565.
- Poehlmann, J., Clements, M., Abbeduto, L. & Farsad, V. (2005). Family experiences associated with a child's diagnosis of fragile X or Down syndrome: evidence for disruption and resilience. *Mental Retardation*, 43, 255-267.
- Pruchno, R.A. & McMullen, W.F. (2004). Patterns of service utilization by adults with a developmental disability: Type of service makes a difference. *American Journal on Mental Retardation*, 109, 362-378.
- QSR (2008). *NVivo 8*. QSR International.
- Quine, L. & Pahl, J. (1987). First diagnosis of severe handicap: a study of parental reactions. *Developmental Medicine and Child Neurology*, 29, 232-242.
- Quine, L. & Rutter, D.R. (1994). First diagnosis of severe mental and physical disability: A study of doctor-parent communication. *Journal of Child Psychology and Psychiatry*, 35(7), 1273-1287.
- Rao, S. (2006). Parameters of normality and cultural constructions of "mental retardation": perspectives of Bengali families. *Disability & Society*, 21, 159-178.
- Reading, J. (1999). Towards equity in service provision: Research feature. *Tizard Learning Disability Review*, 4, 6-15.
- Rogers-Dulan, J. (1998). Religious connectedness among urban African American families who have a child with disabilities. *Mental Retardation*, 36, 91-103.
- Rubin, H. & Rubin, I. (1995). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage Publications.

- Saloviita, T., Itälä, J. & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A Double ABCX model. *Journal of Intellectual Disability Research*, 47, 300-312.
- Schall, C. (2000). Family perspectives on raising a child with Autism. *Journal of Child and Family Studies*, 9, 409-423.
- Scorgie, K. & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, 38, 195-206.
- Scorgie, K., Wilgosh, L. & McDonald, L. (1996). A qualitative study of managing life when a child has a disability. *Developmental Disabilities Bulletin*, 24, 68-89.
- Scorgie, K., Wilgosh, L. & Sobsey, D. (2004). The experience of transformation in parents of children with disabilities: Theoretical considerations. *Developmental Disabilities Bulletin*, 32, 84-110.
- Scott, S. (1994). Mental Retardation. In Rutter, M., Taylor, E., Hersov, L. (Eds.). *Child and Adolescent Psychiatry* (pp. 616-646). Oxford: Blackwell.
- Scottish Executive (2004). *Analysis of Ethnicity in the 2001 Census: Summary Report*. Office of the Chief Statistician: Edinburgh.
- Seigel, S. (1997). Coping with the diagnosis of autism. In: D.J. Cohen. & F.R. Volkmar (Eds.) *Handbook of Autism and Pervasive Developmental Disorder* (pp. 745-766). New York: Wiley.
- Seltzer, M.M., Greenberg, J.S., Floyd, F.J., Pettee, Y. & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106, 265-286.
- Shah, Q. & Sonuga-Barke, E. (1995). Family structure and the mental health of Pakistani Muslim mothers and their children living in Britain. *British Journal of Clinical Psychology*, 34, 79-81.
- Sharp, M.C., Strauss, R.P. & Lorch, S.C. (1992). Communicating medical bad news: Parents' experiences and preferences. *Journal of Pediatrics*, 121, 539-546.
- Shattuck, P.T. & Grosse, S.D. (2007). Issues related to the diagnosis and treatment of autistic spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 129-135.
- Shweder, R.A. (1991). *Thinking through cultures: expeditions in cultural psychology*. Cambridge, MA: Harvard University Press.

- Simmerman, S., Blacher, J. & Baker, B.L. (2001). Fathers' and mothers' perceptions of father involvement in families with young children with a disability. *Journal of Intellectual and Developmental Disability*, 26, 325-338.
- Singer, G., Marquis, J., Powers, L., Blanchard, L., Divenere, N., Santelli, B., Ainbinder, J. & Sharp, M. (1999). A multi-site evaluation of parent to parent programs for parents of children with disabilities. *Journal of Early Intervention*, 22, 217-229.
- Skinner, D.G., Correa, V., Skinner, M. & Bailey, D.B. (2001). Role of religion in the lives of Latino families of young children with developmental delays. *American Journal on Mental Retardation*, 106, 297-313.
- Sloper, P. & Turner, S. (1993). Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine and Child Neurology*, 35, 816-825.
- Smith, B., Chung, M.C. & Vostanis, P. (1994). The path to care in autism: Is it better now? *Journal of Autism and Developmental Discord*, 24, 551-563.
- Solnit, A. & Stark, M.H. (1962). Mourning and the birth of a defective child. *Psychoanalytic Study of the Child*, 16, 9-24.
- Stainton, T. & Besser, H. (1998). The positive impact of children with an intellectual disability in the family. *Journal of Intellectual and Developmental Disability*, 23, 57-70.
- Stanley, M., & Cheek, J. (2003). Grounded theory: Exploiting the Potential for Occupational Therapy. *The British journal of occupational therapy*. 66, no. 4, 143 (148 pages).
- Steier, F. (1991). *Research and Reflexivity*. London: Sage Publications.
- Strauss, A. & Corbin, J. (1990). *Basics of Qualitative Research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.
- Strauss, A. & Corbin, J. (1998). *Basics of Qualitative Research*, 2<sup>nd</sup> edition. London Sage Publications.
- Stubblefield, H.W. (1977). Religion, parents and mental retardation. In C.J. Drew, M.L. Hardman & H.P. Bluhm (Eds.) *Mental Retardation. Social and Educational Perspectives*. Saint Louis: C.V. Mosby Company.
- Summers, S. & Jones, J. (2004). Cross-cultural working in community learning disabilities services: clinical issues, dilemmas and tensions. *Journal of Intellectual Disability Research*, 48(7), 687-694.
- Taanila, A., Jarvelin, M. & Kokkonen, J. (1998). Parental guidance and counseling by doctors and nursing staff: parents' views of initial information and advice for families with disabled children. *Journal of Clinical Nursing*, 7, 505-511.

- Taanila, A., Syrjala, L., Kokkonen, J., & Jarvelin, M. (2002). Coping of parents with a physically and/or intellectually disabled children. *Child: Care, Health and Development*, 28, 73-86.
- Tamm, M. (1999). Relatives as a Help or a Hindrance-A Grounded theory Study Seen from the Perspective of the Occupational Therapist. *Scandinavian Journal of Occupational Therapy* 6, no. 1, 36-45.
- Tates, K., Elbers, E. & Meeuwesen, L. (2002). Doctor-parent-child relationships: a "pas de trios". *Patient Education and Counseling*, 48, 5-14.
- Taunt, H.M. & Hastings, R.P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities*, 37, 410-420.
- Taylor, S. (1983). Adjustment to threatening events: a theory of cognitive adaptation. *American Psychologist*, 38, 1161-1173.
- Teebi, A.S. & El-Shanti, H. (2006). Consanguinity: implications for practice, research, and policy. *Lancet*, 367, 970-971.
- Thorin, E., Yovanoff, P. & Irvin, L. (1996). Dilemmas faced by families during their young adults' transitions to adulthood: a brief report. *Mental Retardation*, 34, 177-120.
- Trent, J.W. (1994). *Inventing the Feeble Mind: A history of mental retardation in the United States*. Berkeley, CA: University of California Press.
- Triandis, H.C. (1995). *Individualism and collectivism*. Boulder, CO: Westview.
- Turnbull, A. & Turnbull, R. (2001). *Families, professionals, and exceptionality: collaborating for empowerment*. Upper Saddle River, NJ: Merrill/Prentice Hall.
- Valentine, D., McDermott, S. & Anderson, D. (1998). Mothers of adults with mental retardation: Is race a factor in perceptions of burdens and gratifications? *Families in Society: Journal of Contemporary Human Services*, 79, 577-584.
- Webb-Johnson, AL (1991). *A Cry for Change. An Asian Perspective on Developing Quality Mental Health Care*. Confederation of Indian Organisations: UK.
- Whitaker, S. (2003). Should we abandon the concept of mild learning disability? *Clinical Psychology*, 29, 16-19.
- Whitcher, K., & Tse, S. (2004). Counselling Skills in Occupational Therapy: A Grounded theory Approach to Explain their Use within Mental Health in New Zealand. *The British journal of occupational therapy*. 67(8), 361-728.
- Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity of qualitative research. *Qualitative Health Research*, 11, 522-537.

Wilgosh, L. & Scorgie, K. (2006). Theoretical model for conceptualizing cross-cultural applications and intervention strategies for parents of children with disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 211-218.

Willig, C. (2001) *Qualitative Research In Psychology: A Practical Guide to Theory and Method*. Buckingham: OUP.

Wing, L. (1998). The history of Asperger Syndrome. In: E. Schopler., G.B. Mesibov. & L.J. Kuncie (Eds.). *Asperger Syndrome or High-Functioning Autism?* (pp. 11-28). New York: Plenum.

World Health Organisation (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organisation.

Wright, D. & Digby, A. (1996). *From idiocy to Mental Deficiency: Historical Perspectives on People with Learning Disabilities*. Routledge: London.

Yaqoob, M., Bashir. & Tareen, K. (1995). Severe mental retardation in 2 to 24-month-old children in Lahore, Pakistan: A prospective cohort study. *Acta Paediatrica*, 84, 267-272.

Yau, M.K.S. & Li-Tsang, W.P.C. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. *The British Journal of Developmental Disabilities*, 45(1), 38-51.

Zuniga, M.E. (1998). Families with Latino roots. In: E.W. Lynch & M.J. Hanson (Eds.). *Developing cross-cultural competence* (pp. 209-250). Baltimore: Brookes.



# APPENDICES

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## **APPENDIX 1**

**Approval letter from Lothian Ethics Committee**

**Lothian Local Research Ethics Committee 03**

Deaconess House  
148 Pleasance  
Edinburgh  
EH8 9RS

Telephone: 0131 536 9022  
Facsimile: 0131 536 9346

30 April 2009

Ms Alia Ul-Hassan  
Trainee Clinical Psychologist  
NHS Lothian  
Learning Disability and Autism Team  
3 Rillbank Terrace  
Edinburgh  
EH9 1LL

Dear Ms Ul-Hassan

**Full title of study:** A grounded theory account of South Asian parents' understanding of their child's diagnosis of a learning disability and/or an Autistic Spectrum Disorder: the influence of cultural beliefs and impact on adjustment and coping.

**REC reference number:** 09/S1103/16

Thank you for your letter of 17 April 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by the chair on behalf of LREC 3.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below. Please note however Alex Bailey, Scientific Adviser (tel. 0131 536 9050) will be getting in touch with you regarding the point you wished clarification on i.e. Informing GP's.

**Ethical review of research sites**

The favourable opinion applies to the research sites listed on the attached form.

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		20 March 2009
Protocol	1	20 March 2009
Investigator CV	CI	20 March 2009
Application	1	20 March 2009
Letter of invitation to participant	1 Parent Group	23 March 2009
Investigator CV	Quayle	23 March 2009
C I Declaration		23 March 2009
Interview Schedules/Topic Guides	1	20 March 2009
Compensation Arrangements		04 February 2009
Letter from Sponsor		06 March 2009
Summary/Synopsis	1	20 March 2009
Justification of small sample size		17 April 2009
Response to Request for Further Information		17 April 2009
Participant Consent Form	2	17 April 2009
Participant Information Sheet: PIS	2	17 April 2009

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review –guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

09/S1103/16

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

**Chair**

Dr Christine West LREC 3

Email: [joyce.clearie@nhslothian.scot.nhs.uk](mailto:joyce.clearie@nhslothian.scot.nhs.uk)

*Enclosures:*

*"After ethical review – guidance for researchers" [SL-AR1 for CTIMPs, SL-AR2 for other studies]  
Site approval form*

*Copy to:*

*Ms Elspeth Currie  
[R&D office for NHS care organisation at lead site]*

## **APPENDIX 2**

### **Participant information letter**



### **Participant Information Sheet**

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. ***Take time to decide whether or not you wish to take part.***

**Researcher:** Alia Ul-Hassan, Trainee Clinical Psychologist

**Address:** Learning Disability and Autism Team, 3 Rillbank Terrace, Edinburgh, EH9 1LL

#### **Study title**

The role of culture in parents' responses and understanding of their child with a learning disability and/or an Autistic Spectrum Disorder.

#### **What is the purpose of the study?**

The purpose of the study is to carry out interviews to explore South Asian parents' experiences of their child receiving a diagnosis of a learning disability and/or an autistic spectrum disorder. Looking at how parents understand the diagnosis and the factors that might impact on this is important in order to give us an insight into how parents adjust and cope with their child and the diagnosis.

Your role in this study would be greatly valued because there are not enough studies which look at this area and by taking part you will be contributing to increased knowledge about this important subject area.

#### **Why have I been chosen?**

You have been chosen because you are of a South Asian background and you have a child who has a learning disability and/or an autistic spectrum disorder.

#### **Do I have to take part?**

It is entirely up to you whether or not to take part. If you decide to take part you are still free to withdraw at any time and you do not need to give a reason for this. A decision to withdraw at any time or a decision not to take part will not affect the standard of care your child and family receives.

#### **What will happen to me if I take part?**

Before you agree to take part, there will be the option for you to attend a Parent Group to get more information about the project. However, if you find that the information in this

leaflet is sufficient, you can participate in the research without attending the Parent Group.

If you agree to take part you will be asked to sign a consent form which you will be given to keep with this information sheet. A copy of the consent form will also be kept by the researcher.

If you decide to take part you and the researcher will agree where the best place would be to carry out the interview. This could be at the clinic where you and your child is seen or at your home. The interview will last between 1 and 2 hours. This time can be split between two separate occasions if necessary. Therefore, taking part in this study may involve meeting with the researcher on two separate occasions if the interview is not completed after the first meeting.

The interview will be conversational in style and you are free to answer in your own way. There are no right or wrong answers.

With your consent the researcher will record the session(s) using a digital voice recorder. Before beginning the recording, the researcher will show you the equipment and how it works. You may stop the recording at any time during the interview.

Some people may find some of the questions upsetting. If this happens you can decide not to answer these questions and you will have the opportunity to talk to the researcher's clinical supervisor (Dr Gill Kidd) about how you are feeling. The researcher will also give you the opportunity at the end of the interview to discuss any issues related to the questions asked.

The care your child receives will not be affected by your decision not to answer particular questions.

### **Will my taking part on this study be kept confidential?**

All information collected during the study will remain confidential.

The researcher will use the recording of the interview to make a transcription. This means typing out the interview onto a word processor so that the researcher can develop a deeper understanding of the experiences you have shared. After the interview has been typed out, the audio-recordings will be destroyed. Any information such as your name, your child's name, specific places and any other identifying information will be removed. In this way no-one can identify you from information that we collect.

### **What will happen to the results of the research study?**

Findings from the study will be presented in a written report to the University of Edinburgh as coursework for the degree of Doctorate in Clinical Psychology. It may be possible in the future for this study to be published in academic journals or presented at conferences. Participants' names will not be used in any publications and the service they attended will not be identified.

If you would like a copy of the results, these can be obtained from the researcher.



**Who is organising and funding the research?**

This study is part of the coursework for the degree of Doctorate in Clinical Psychology at the University of Edinburgh.

Unfortunately, travel expenses (or any other expenses) are not available for anyone participating in the study.

**Who has reviewed the study?**

The study has been reviewed by the local ethics committee and the Course Organisation Group of the East of Scotland Clinical Psychology Programme.

**Contact for further information?**

For further information please contact the researcher: Alia Ul-Hassan, Trainee Clinical Psychologist, Learning Disability and Autism Team on 0131 662 2201.

The researcher is being supervised by **Dr Gill Kidd** who is a Consultant Clinical Psychologist in the Learning Disability and Autism Team. She can also be contacted on 0131 662 2201 if you wish to discuss this study with her before agreeing to take part.

***Thank you for taking the time to read this information sheet.***



### **APPENDIX 3**

#### **Participant Consent form**



### **Participant Consent Form**

**Study title:** The role of culture in parents' responses and understanding of their child with a learning disability and/or an Autistic Spectrum Disorder.

**Researcher:** Alia Ul-Hassan. Learning Disability and Autism Team, 3 Rillbank Terrace, Edinburgh, EH9 1LL.

**Please read the following statements and initial the boxes.**

1. I have read the information sheet and have had the opportunity to ask questions about the study. ☐
2. I understand that it is my choice to help with the study and I can withdraw at any time, without giving a reason and without the care of my child being affected in any way. ☐
3. I consent to an audio-tape of the interview being made and the recording being typed out. ☐
4. After the interview has been typed out, and all names, places and identifiers have been removed I understand that the researcher may publish direct quotations. ☐
5. I consent to taking part. ☐

**Parent/carer signature:**

**Please print name:**

**Date:**

## **APPENDIX 4**

### **Participant summaries**

**Participant Summaries**  
LD = learning disability

Participant	Gender/ Age	Education Level of parent	Ethnicity	Main language spoken at home	Religion (if any)	Number of children with disabilities	Relation to child	Diagnosis of child(ren)	Age of child(ren)
1	F 35 years	High school	Second generation Pakistani	English	Muslim	2	Mother	Autism/LD (both children)	10 and 12 years
2	F 35	High school	Second generation Pakistani	English/ Punjabi	Muslim	1	Mother	LD (unknown type/cause)	9 years
3	M 52 years	High school	First generation Pakistani	English	Muslim	1	Father	LD (unknown type/cause)	12 years
4	F 27	Degree level	Second generation Pakistani	English	Muslim	1	Mother	Autism/LD	6 years
5	F 45 years	Degree level	First generation Pakistani	English	Muslim	1	Mother	Down's Syndrome/ Autism/LD	9 years
6	F 44 years	High school	First generation Pakistani	English/ Urdu	Muslim	1	Mother	Autism/LD	12 years
7	M 49 years	Degree level	First generation Pakistani	English/ Urdu	Muslim	2	Father	Autism/LD (both children)	9 and 11 years

## **APPENDIX 5**

### **Interview schedule**

## Interview Schedule

Thank for participation

Brief summary of the aim of the interview (as a reminder)

Answer any questions or concerns before we start

### **Circumstances of child and family (to open up the interview):**

- Family member interviewed
- Ethnic origin of family member interviewed
- Religion of family (if any)
- First language of family member interviewed
- What is the main language spoken at home?
- Who else is in the family?
- Number of children with disabilities
- Circumstances of the child with LD and/or ASD to be discussed
  - Age
  - Gender
  - Diagnosis

### **Initial questions**

- When did you first notice there was a problem with your child?
- How did you go about getting help?

### **Process and experience of disclosure of diagnosis**

- When was the diagnosis given?
- Who was this given by?
- How was this done?
- What was this time like for you?
- **How would you summarise your experience of the process of assessment and diagnosis of your child?** Helpful and unhelpful things.
- **Can you tell me a bit about how the diagnosis affected you/your family?**
- **What challenges arose for you once the diagnosis was made?**
- **Views of spouse/wider family in above areas.**
  - Do they feel differently about things?

### **Parental perceptions of the child with disabilities**

- How did you initially make your own sense of your child's difficulties?
- Who or what helped you to make sense of the difficulties?
- **What are the views of your spouse? Wider family?**
  - Did they feel differently about things?
- **Has the way you have understood your child's difficulties changed over time?**

**Process of sharing the news about the child's diagnosis and consequences of this, including support post-diagnosis**

- Support from family, friends and services

**Role of child with disabilities in the family, including positives**

**Daily life with the child (linked with issues around support?)**

**Ending questions**

- Is there anything else that is important to talk about that we may have missed?
  - How did you find the experience about talking about these issues today?
- 

**Probing questions**

- What experiences come to mind?
- Tell me what happened?
- Tell me your thoughts and feelings when...
- How, if at all have your thoughts and feelings changed?
- Are there any particular experiences that come to mind?
- Looking back, are there any particular occasions that stand out for you?
- What helped you to manage? Who has been helpful?
- If someone else was going through the same thing now, what would you say to them?

**Prompting questions**

- I'm interested in...can you tell me more about that?
- What do you mean by that?
- What is X like?
- What did you do?
- How did you feel?
- How did others react?
- What are you thinking right now?
- What were your thoughts then?

## **APPENDIX 6**

### **Example of a coded transcript**



Extracts of transcript 1, Participant 1

Extract 1	
R: So today I wanted to talk a little bit about the process of assessment, things that were helpful, unhelpful and so on	
P: when we got the diagnosis for autism, the doctor said it was autism and it was like, it was point blank. It was a relief he had a diagnosis so it wasn't me just being senile about it. I thought, I head about autism, you know read reports but really had no idea about it. but it was a relief at least I was right, there was something wrong with him. It was just me thinking there was something wrong. Before....you know I was like taking the blame for myself, I thought it was something to do with the way I was bringing them up, something about what I was doing to make him have problems. I had a lot of tension because I didn't know. His development was just off. So yeah it was a relief.	<p>"point blank", certainty? Relief Not me being senile Some knowledge on autism Really no idea about it! Relief! Concerns legitimised</p> <p>Prenonsly taking the blame Is it my fault? Attributing blame to self prenonsly Feeling tension Noticing his development was 'off' <u>RELIEF</u></p>
R: So what happened afterwards for you and your family?	
P: You mean after the diagnosis was given?	
R: Yeah	
Well the doctor who told us the diagnosis was really helpful. She asked us what we know about autism. We told her we didn't know	<p>Finding doctor helpful Being asked about our Knowledge.</p>

<p>anything really. She spent quite a lot of time talking to us about it. The most helpful thing was being given information about how it would affect my child's life, she gave good specific information. She told us how to get support, DLA and things like that. It made us feel a bit more confident about what to do next.</p>	<p>Doctor spending time with us being given information Information about implications being given good information Advice about getting support Feeling bit more confident</p>
<p>R: So it sounds like the diagnosis was a starting point for you..</p>	
<p>P: yeah cos I didn't know what to do next, (DOCTOR) told me about the things I could do. I think its really important that parents get a diagnosis because without it services just shut their door on you, they don't want to do. If you have a diagnosis, that label, the doors open for you and you can get the help you need. You don't know about support groups, you don't know who to ask about things before a diagnosis. Once you have the diagnosis, you can get loads of help, meet other parents with similar circumstances, that is so helpful. So for me the diagnosis was an advantage. I went to the support group, I got a place at the children's centre. The process was all just speeded up.</p>	<p>not knowing what to do next Being told about possibilities getting a diagnosis is important no diagnosis = no service doors being shut on you labels = open doors before a diagnosis → lack of knowledge getting a diagnosis means getting help. getting to meet other parents Finding it helpful Diagnosis as an advantage going to a support group Process speeded up.</p>
<p><b>Extract 2</b></p> <p>R: Can I just take you back to when you were saying about hiding a child's problem in our</p>	

community. What do you think the fears are about that?	
P: It is the fact people talk, people gossip about it. I think because they don't...they look into the future. It's the arranged marriages thing. If someone comes in looking to marry say if a family has other kids as well as the disabled one. It would be seen as a disadvantage to marry into that family when there is a disabled child. It would make the sibling less suitable, it is very judgemental.	People talk, people gossip Looking into future Arranged marriages Effect of disability on marriage Disability as a disadvantage Impact on rest of family Very judgemental!
R: what do you think about that?	
P: I don't think about that. I am different with my children. with my children to be married, I don't know what will happen, will they understand about marriage. It is difficult for children with autism to build a relationship. I don't have any other children, so I don't worry about marriage and stuff like that.	Perceiving there to be a difference in my outlook Not sure about future & marriage Acknowledging limitations of autism Making a decision not to worry.
R: right...okay.	
P: Its also difficult when people live with their extended families or have very close contact with them. My mum doesn't like me to be open about my children. she tells don't tell anyone. She doesn't want people to gossip. She thinks I wont get a suitable candidate for my sons to get married.	living with extended families Family prefer not to be open about children Don't tell anyone Fear or gossip Ramifications for marriage prospects.
At the start I tried to respect my mum's wishes	Trying to respect mums wishes

not to tell anyone but as my child got older and as I accepted things, I didn't see no reason for me to hide my son away. I have started to tell people about it...if you don't share these things, people are never gonna learn about disability and they will always think it's a bad thing...I want them to see its not.

Accepting situation  
Feeling no reason to hide son  
Telling people about autism  
Want to share the autism  
Autism not a bad thing  
Spreading awareness

### Extract 3

When you get a diagnosis, a real label you can say to them this is what my child has got so I don't know why you are blaming me but if there is a long long battle for a diagnosis, then these mothers need to put up with being blamed for all that time and sometimes even when they get a diagnosis, the blame factor is still there....you know they think we have done something wrong to get these kids, we have done something wrong in life, we have been cursed. I think that is ridiculous. I mean what wrong have we done in life? Have we murdered anyone? I just feel it is a blessing from Allah, if he has given us children like this then we must have some qualities in us to make us manage. We are with our children, we don't give up.

Using a label to explain  
Using label to exonerate self from blame.  
Using label with people in under society.  
Putting up with being blamed  
The blame factor  
Perceptions of mother inflicting autism  
Being cursed  
Done something wrong  
think it's ridiculous  
Belief it is a blessing from Allah  
Parents have special qualities  
not giving up.

## **APPENDIX 7**

### **Extract of research journal 1**

After completing my undergraduate degree, I worked as a volunteer befriender for a young South Asian boy with autism and his family. Although my role was practical and activities-led, I often had the impression that this boy's mother valued engaging in discussions with me about her experiences of having a child with autism. She often raised cultural issues in relation to these experiences. Developing a relationship with the family allowed me to gain my first real insight into contextual factors that can impact upon families who have a child with autism. I also felt that being of a South Asian origin allowed me to identify with some of the issues she discussed. This befriending role also brought to the fore many thoughts in me about a member in my extended family with a learning disability and about how his marginalisation from within my community angered and confused me.

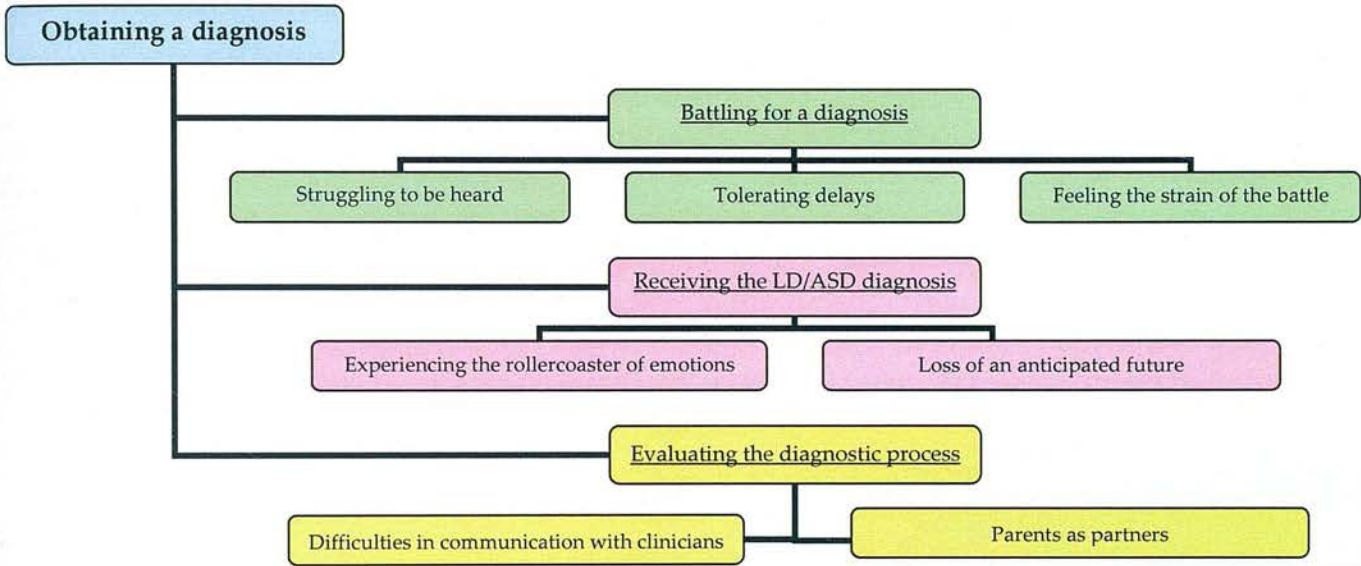
During my clinical psychology training, I have developed a keen interest in how issues of difference, for example in terms of ethnicity, religion, sexuality and ability level can impact on an individual's life and how others perceive them. I felt a natural inclination to working with the learning disability population for my specialist placement and was aware of many issues that face them as a group in terms of disadvantage and discrimination. I was aware that being of an ethnic minority background might magnify this experience even more. During my placement, I worked with one Iraqi mother who was struggling to come to terms with her daughter's learning disability and she frequently spoke to me about how issues of culture made this already difficult adjustment process even harder.

Throughout my reading, I have become aware that the majority of the literature concerning children with learning disabilities and their families from ethnic minority communities focuses on documenting the experiences of South Asian parents in terms of inequalities in healthcare, housing and education etc. I formulated my idea for this thesis on the basis of a lack of literature in relation to South Asian parents' experiences of the process of receiving a diagnosis for their child and subsequent adjustment. Given the bias towards negative outcomes in the literature in relation to this client group, I expect to be presented with a picture of struggle and grief. I also expect to hear about language and cultural barriers in accessing appropriate services as well as possible parental perceptions of discrimination in service provision. However, I also hope to be able to elicit positive elements of parents' experiences.

## **APPENDIX 8**

**Core category: Obtaining a diagnosis**

Core category: Obtaining a diagnosis

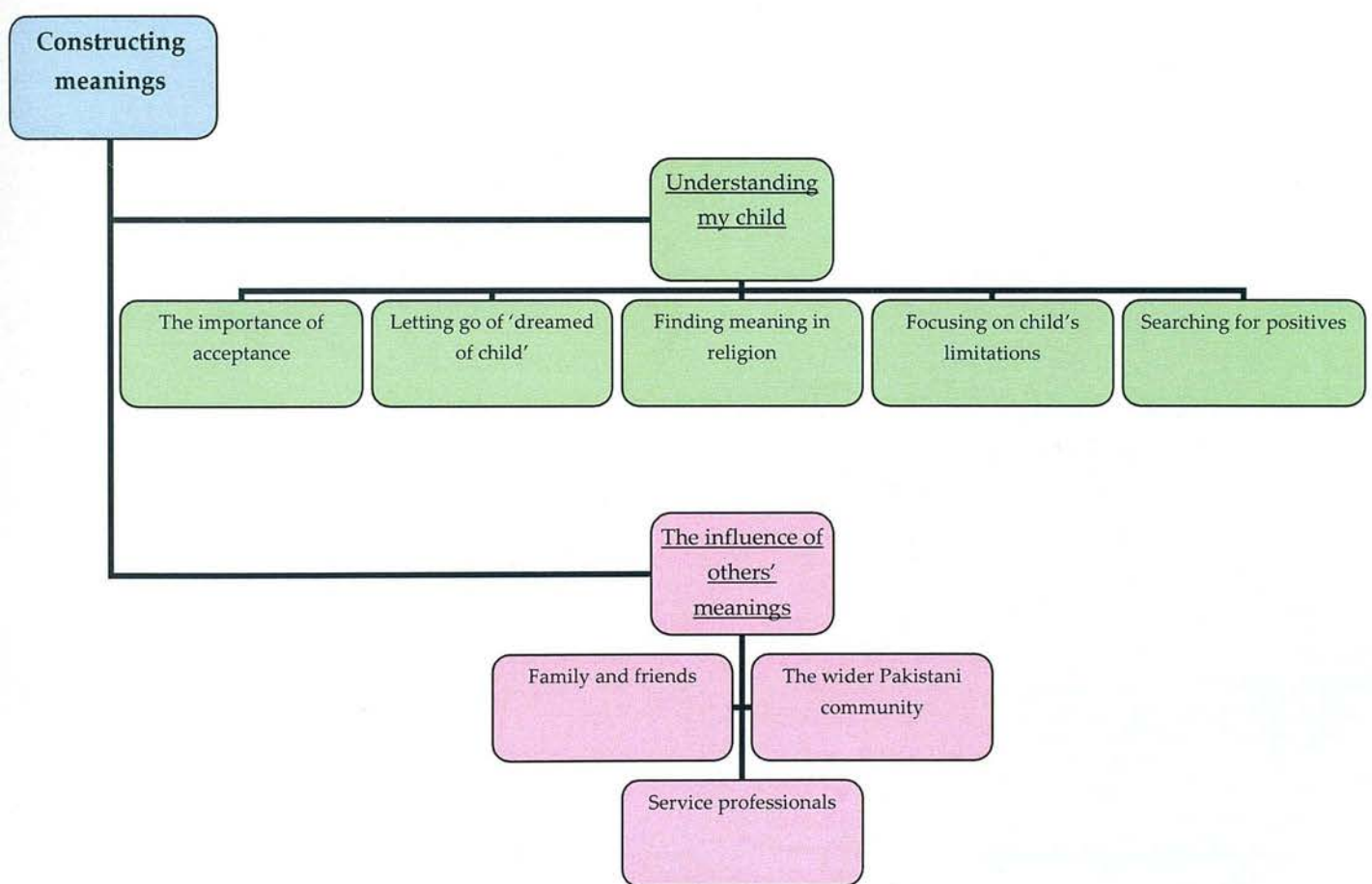




## **APPENDIX 9**

**Core category: Constructing meanings**

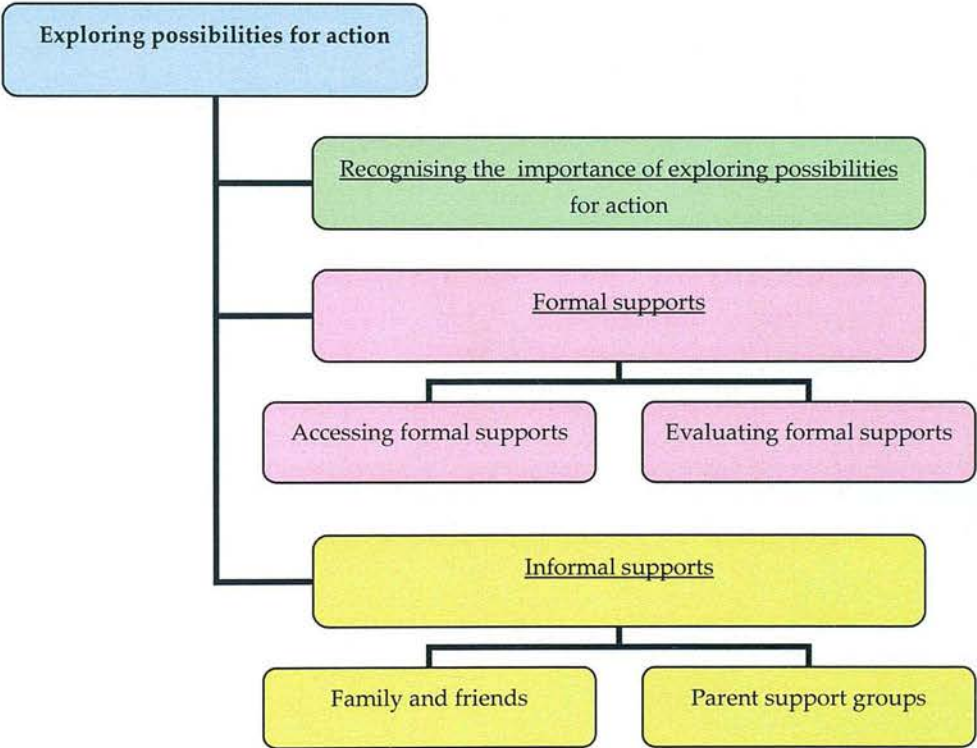
Core category: Constructing meanings



## **APPENDIX 10**

**Core category: Exploring possibilities for action**

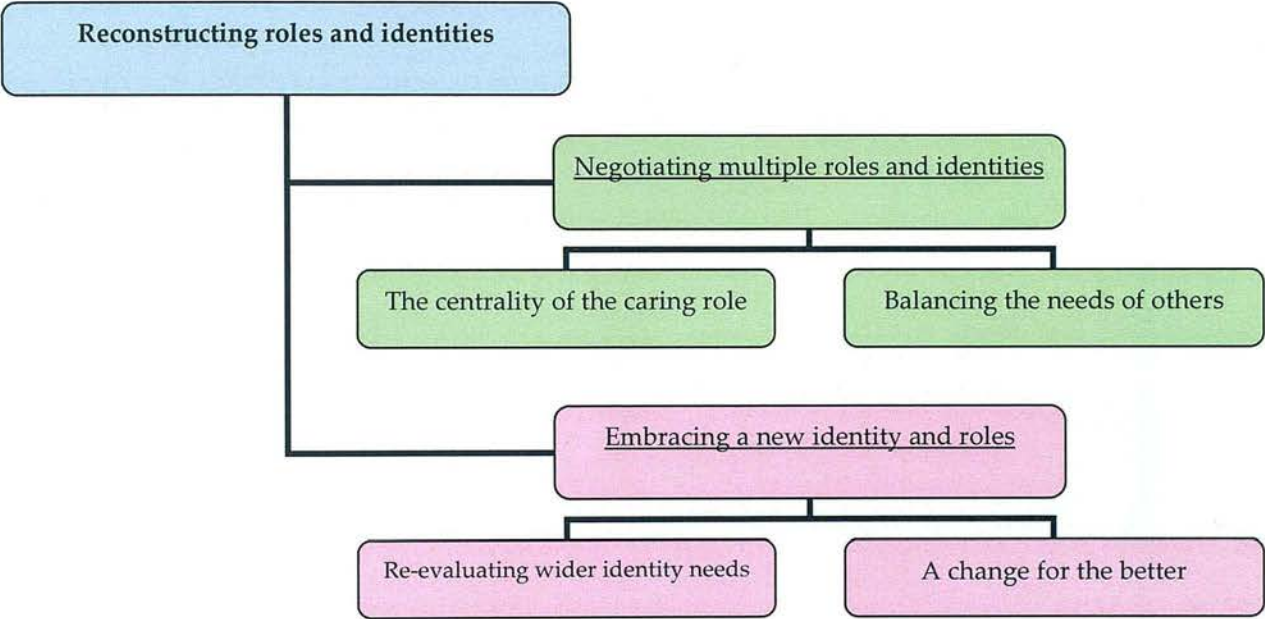
Core category: Exploring possibilities for action



## **APPENDIX 11**

**Core category: Reconstructing roles and identities**

Core category: Reconstructing roles and identities



## **APPENDIX 12**

**Hypothesised model of the adjustment process of parents following a diagnosis of LD/ASD for their child.**

